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TITLE: The Effects of Supportive and Nonsupportive Behaviors on the Quality of Life of Prostate Cancer Patients and Their Spouses

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supportive behaviors mediate the relationship between illness uncertainty and QOL and illness uncertainty and psychological well-being? To date, we have successfully recruited, at baseline, 132 patients and 114 spouses. Preliminary baseline results suggest that patients' QOL is significantly related to perceptions of marital satisfaction, social support and unsupportive behaviors. These relationships did not hold true to spouses.

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FOREWORD

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X For the protection of human subjects, the investigator(s) adhered to policies of applicable Federal Law 45 CFR 46.

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INTRODUCTION

Research on prostate cancer has not, as yet, identified how patients' and their spouses' supportive (e.g., giving advice/emotional support) and nonsupportive behavior (e.g., criticizing/avoiding partner) affect and are affected by their: 1) feelings of disease uncertainty, 2) psychological well-being, 3) perceptions of control, and 4) qualify of life (QOL). This two year prospective observational survey study explores these issues among approximately 150 early stage prostate cancer patients and their spouses are asked to complete a questionnaire packet before surgery (radical prostatectomy), and at one, six and 12 months post-surgery. The questionnaire packet assesses perceptions of disease uncertainty, supportive and unsupportive behaviors, perceptions of control, marital satisfaction, and quality of life. The specific predictions to be tested in the study are:

HI: Greater levels of illness uncertainty among prostate cancer patients and their spouses will predict significantly lower levels of perceived control.

H2: Patient and spouses with low levels of uncertainty and/or high perceived control will need primarily informational and social and instrumental support; individuals with high levels of illness uncertainty and/or low perceived control will need emotional, network and esteem support.

H3: Greater illness uncertainty and perceived inadequacies in social support, especially in areas most needed, will correlate positively with frequency and types of non-supportive behaviors.

H4: Social support and non-supportive behaviors will mediate the relationship between illness uncertainty and QOL, and between illness uncertainty and psychological well being.

H5: Higher levels of uncertainty and lower perceived control will predict poorer QOL, especially shortly after surgery.

H6: Spouses will experience poorer QOL than patients.

BODY

During the first year of the grant, we have achieved successfully many of our preliminary objectives as provided in our statement of work. These are listed below:

Task 1: Plan and develop a tracking system with the Duke Department of Urology to recruit study participants (months 1-2)

Progress: We have initiated and implemented a very successful recruitment procedure which has resulted in reaching close to 90% of all early stage prostate cancer patients (A & B) who visit the urology clinic.

Task 2: Develop and test study questionnaire with 10 prostate cancer patients and their spouses (months 1-2).

Progress: We have not only pilot tested this questionnaire, but have also designed the one, six, and twelve-month questionnaires. These questionnaires are exhibited in Appendices B-E. (The baseline questionnaire is presented in Appendices B. We have provided a copy of both the patient version and the spouse version of the baseline questionnaire. However, for the one, six, and twelve-month post surgery questionnaires, Appendices C-D, we have included only the patient version. The variance in the two questionnaires, spouse and patient, is minimal and thus remains consistent throughout the various time points.)

Task 3: Mail-out study questionnaires to 150 prostate cancer patients and their spouses along with reminder notices and phone calls (months 3-27).

Progress: We are in our final month of collecting baseline data, and in early October we will begin sending out our 12-month post-surgery follow-up questionnaire. As of September 15, 1999, we have tracked 256 patients through Dukes Urology Clinic. Of these 256 patients: 137 are enrolled, 38 are actively being recruited, 14 never sent back their questionnaire after all reasonable efforts were made, 16 refused to participate, and 51 were ineligible (28 chose treatment other than surgery, 9 diagnoses of another cancer within less than 5 yrs, 4 due to extenuating circumstances (i.e. surgical complications), 3 were mentally incompetent, 2 had recurrent prostate cancer, 2 had been diagnosed more than one yr. ago, 2 were prisoners and 1 patient was too advanced after clinical exam).

We have chosen to enroll patients that do not have a spouse or partner. These 13 patients were sent questionnaires without questions that assessed relationship constructs (e.g. social support, marital satisfaction).

On a few occasions we were unable to recruit patients before they had their surgery. However, due to their interest in participating these 5 patients were enrolled at the one-month post-surgery follow-up.

Along with the 137 patients that are currently enrolled in the study, 119 of their partners (spouses or significant others) have completed questionnaires and are enrolled in the study.

Table 1 summarizes the current recruitment data:

Table 1: Recruitment Summary as of September 15, 1999

| Questionnaire Time point | Total Sent | Total Received | Patients with a Partner (2) | Patients with out a Partner (3) | Partners (4) | Matched Pairs (Dyads) (5) |
|-----------------------------|---------------|-------------------|-----------------------------|---------------------------------|--------------|------------------------------|
| Baseline | 289 | 246 | 119 | 13 | 114 | 112 |
| One month Follow-up (1) | 194 | 180 | 82 | 5 | 82 | 81 |
| Six Month Follow-up | 86 | 74 | 35 | 5 | 34 | 34 |
| Twelve Month Follow-up | 0 | 0 | 0 | 0 | 0 | 0 |

⁽¹⁾ Some patients who completed baseline questionnaires were lost at follow-up for various reasons. 26 patients were lost because their post surgical pathology report indicated advanced disease, 3 changed their treatment choice, and 1 was lost due to refusal. Thus, 98 patients remained eligible for the one-month follow-up as compared with 128 patients that were enrolled at Baseline and have had their surgery. 9 patients have not yet had their surgery.

(2) This column represents the number of patients that completed the questionnaires who have a partner (spouse or significant other).

(4) This column represents the number of partners (spouses or significant others) that completed the questionnaires.

⁽³⁾ This column represents the number of patients that completed the questionnaires who do not have a partner (spouse or significant other).

⁽⁵⁾ This column represents the number or couples (patients and their spouses or significant others) that completed the questionnaires.

Task 4: Conduct analyses on baseline data.

Progress: Baseline data analyses will begin during the first week in October. However, we have had an abstract based on preliminary analyses of 72 patients and their spouses, accepted to the Pan American Congress of Psychosocial and Behavioral Oncology Conference to be held October 20th – 23rd in New York City. This abstract is included in Appendix A.

Tasks 5-8: Conduct analyses on the one, six and twelve month post-surgical data and write-up overall project paper(s).

Progress: These activities will begin to take place starting in February of the year 2000.

KEY RESEARCH ACCOMPLISHMENTS

We have initiated and implemented a very successful recruitment procedure which has resulted in reaching close to 90% of all early stage prostate cancer patients (A & B) who visit the Duke Medical Center's urology clinic.

> Developed and distributed to patients and their spouses the baseline, and one, six, and 12

month post-surgery questionnaires.

➤ Have achieved a very satisfactory return rate from patients; 85% at baseline, 86% at the one-month post surgery time point and 87% at the six-month post-surgery time point. The high return rate was similar among the spouses; 85% at baseline, 88% at the one-month post surgery time point and 85% at the six-month post-surgery time point.

➤ Will be presenting an abstract of baseline results to the Pan American Congress of Psychosocial and Behavioral Oncology Conference to be held October 20th – 23rd in New

York City.

REPORTABLE OUTCOMES

Abstract entitled: "Correlates of Quality of Life Among Prostate Cancer Patients and Their Spouses" to be presented at the Pan American Congress of Psychosocial and Behavioral Oncology Conference to be held October 20th – 23rd in New York City

CONCLUSIONS

An in-depth analysis of our baseline data will commence shortly. However, based on very preliminary baseline data (pre-surgery) we are finding that:

> Women report poorer quality of life than the patient, especially in areas that involve

emotional outcomes (e.g., mental health).

The reported quality of life of the patient is correlated significantly with their perceptions of marital satisfaction, disease uncertainty, perceived spousal support and perceived spousal critical and avoidant behaviors. These outcomes are not consistently related to spouses' quality of life. Therefore, it may be the patient's perceptions of relational issues that may affect more powerfully his quality of life than that of the spouse.

REFERRENCES

Not applicable at this time.

Appendix A Abstract

"Correlates of Quality of Life Among Prostate Cancer Patients and Their Spouses" Isaac M. Lipkus*, Elizabeth Clipp, Richard Potthoff, and Cary Robertson

Duke University Medical Center, Durham, North Carolina, United States

There has been little research exploring how prostrate cancer patients and their spouses' feelings of disease uncertainty, perceived social support, negative social interactions (i.e., critical and avoidant behaviors), and marital satisfaction affect their own and their partners' quality of life. We explored these influences among 72 early stage prostate cancer patients and their spouses shortly before having surgery (radical prostatectomy).

Patients' emotional and social well-being, as assessed by the SF-36, were most consistently related to perceptions of their disease uncertainty, spousal support, degree to which they viewed their spouses as critical and avoidant, and to marital satisfaction. Spouses' quality of life was related less consistently to their own perceptions of these outcomes. Patients with wives that expressed greater marital satisfaction reported enhanced emotional well-being. However, spouses' quality of life was unrelated to patients' perceptions of their own disease uncertainty, perceived spousal support, spouses' negative and avoidant behaviors and marital satisfaction. Patients reported better emotional well-being, more energy/less fatigue, and less bodily pain than reported by their spouses. These data suggest that in contrast to their spouses, quality of life among men with early stage prostate cancer, prior to surgery, is related strongly to their feelings of disease uncertainty, to the nature of support they feel from their spouses, and to the quality of their spousal relationships. Future studies aimed at assessing quality of life in men with prostate cancer should take accounts from both members of the spousal relationship, focusing especially on the nature of support experienced by men between diagnosis of prostate cancer and surgical intervention.

Appendix B Baseline Questionnaires

Patient with a Spouse Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage paid envelope before your treatment for prostate cancer begins.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your wife, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at 919-956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

| Foday's date: / Month Da | y Year | | |
|--|---------------|---|--------|
| Name: | | | - |
| Home Address: | Street | | Apt. # |
| City | State | Zip Code | |
| Home Phone Number: () | | <u> </u> | |
| Date of Birth:// | | | |
| What is your highest level of e 1 Grade school 2 Some high school 3 High school graduate 4 Some college 5 College graduate 6 Graduate education | е | | |
| Which of the following best de 1 White, not of His | spanic origin | ા or ethnic backgroા Hispanic origin | und? |

9

| A8. | Which of the following best describes your current relationship? |
|--|--|
| | Living with spouse or partner In a significant relationship, but not living together Not in a significant relationship |
| A9. | What is your current marital status? |
| · | 1 Never married 2 Married 3 Separated 4 Divorced 5 Widowed |
| A10. | How long have you been married/separated/divorced/widowed? years |
| A11. | Who else lives in your household besides yourself? (Please check all that apply.) |
| - Andrews - Andr | 1Your husband/wife 2Your mother 3Your father 4Your children 18 or under —> How many? 5Your children over 18 —> How many? 6Sister(s) —> How many? 7Brother(s) —> How many? 8Grandchildren —> How many? 9Grandparent(s) —> How many? 10Other relatives —> How many? 11Other non-relatives —> How many? 12I live by myself. |
| A12. | Here are several broad income ranges. Please select the range that most closely approximates <u>your</u> yearly household income, before taxes, from all sources, including social security. |
| 2 3 4 5 6 7 | 0 - \$4,000 \$4,001 - \$9,000 \$9,001 - \$18,000 \$18,001 - \$30,000 \$30,001 - \$40,000 \$40,001 - \$50,000 \$50,001 - \$60,000 Above \$60,000 |
| A13. | Altogether, how many people live on this income? |
| Accountant into carbonate March | People. |

Do you have any of the following illnesses or conditions at the present time?

| | | | umer | | | |
|--------------------------------------|--|----|--|------------|----------|--------------|
| ILLNESS / CONDITION Circle No or Yes | | | If YES, circle how much the illness interferes with your daily activities. | | | |
| Exa | mple; Asthma | No | Yes | Not At All | A Little | A Great Deal |
| В1 | Anemia | No | Yes | Not At All | A Little | A Great Deal |
| B2 | Arthritis or rheumatism | No | Yes | Not At All | A Little | A Great Deal |
| В3 | Asthma | No | Yes | Not At All | A Little | A Great Deal |
| B4 | Cancer or leukemia | No | Yes | Not At All | A Little | A Great Deal |
| B5 | Circulation trouble in arms, legs, or feet | No | Yes | Not At All | A Little | A Great Deal |
| B6 | Depression, anxiety or emotional problems | No | Yes | Not At All | A Little | A Great Deal |
| B7 | Diabetes | No | Yes | Not At All | A Little | A Great Deal |
| B8 | Effects of Polio | No | Yes | Not At All | A Little | A Great Deal |
| В9 | Effects of stroke | No | Yes | Not At All | A Little | A Great Deal |
| B10 | Emphysema or chronic bronchitis | No | Yes | Not At All | A Little | A Great Deal |
| B11 | Epilepsy/seizures | No | Yes | Not At All | A Little | A Great Deal |
| B12 | Glaucoma | No | Yes | Not At All | A Little | A Great Deal |
| B13 | Heart Disease | No | Yes | Not At All | A Little | A Great Deal |
| B14 | High blood pressure (greater than 140/90) | No | Yes | Not At All | A Little | A Great Deal |
| B15 | Kidney disease | No | Yes | Not At All | A Little | A Great Deal |
| B16 | Liver disease | No | Yes | Not At All | A Little | A Great Deal |
| B17 | Multiple Sclerosis | No | Yes | Not At All | A Little | A Great Deal |

| | LLNESS / CONDITION | | No or | If YES, circle how much the illness interferes with your daily activities. | | | |
|-----|---|----|-------|--|----------|--------------|--|
| B18 | Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome | No | Yes | Not At All | A Little | A Great Deal | |
| B19 | Other urinary tract disorders (including prostate trouble) | No | Yes | Not At All | A Little | A Great Deal | |
| B20 | Parkinson's Disease | No | Yes | Not At All | A Little | A Great Deal | |
| B21 | Severe memory problems such as Alzheimer's or other dementing illness | No | Yes | Not At All | A Little | A Great Deal | |
| B22 | Skin disorders such as pressure sores, leg ulcers, or severe burns. | No | Yes | Not At All | A Little | A Great Deal | |
| B23 | Thyroid or other glandular disorders | No | Yes | Not At All | A Little | A Great Deal | |
| B24 | Tuberculosis | No | Yes | Not at All | A Little | A Great Deal | |
| B25 | Stomach Ulcers | No | Yes | Not at All | A Little | A Great Deal | |
| B26 | Leg Amputation(s) | No | Yes | Not at All | A Little | A Great Deal | |

Please continue to the next page of the questionnaire.



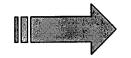
The following statements are about your thoughts and feelings <u>since your</u> <u>diagnosis of prostate cancer.</u> Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-----|--|----------------------|----------|-----------|-------|-------------------|--|
| | EXAMPLE: The purpose of each Treatment is clear to me. Disagree | | | Undecided | Agree | Strongly Agree | |
| C1 | I do not know what is wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C2 | I have a lot of questions without answers. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C3 | I am unsure if my illness is getting better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C4 | It is unclear how bad my pain will be. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C5 | The explanations they give about my condition seem hazy to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C6 | The purpose of each treatment is clear to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C7 | When I have pain, I know what this means about my condition. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C8 | I do not know when to expect things will be done to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C9 | My symptoms continue to change unpredictably. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C10 | I understand everything explained to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |

| • | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-----|---|----------------------|----------|-----------|-------|-------------------|--|
| C11 | The doctors say things to me that could have many meanings. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C12 | I can predict how long my illness will last. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C13 | My treatment is too complex to figure out. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C14 | It is difficult to know if the treatments or medications I am getting are helping. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C15 | There are so many different types of staff, it is unclear who's responsible for what. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C16 | Because of the unpredictability of my illness, I cannot plan for the future. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C17 | The course of my illness keeps changing. I have good days and bad days. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C18 | It is vague to me how I will manage my care after I leave the hospital. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C19 | I have been given many differing opinions about what is wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C20 | It is not clear what is going to happen to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C21 | I usually know if I am going to have a good or bad day. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C22 | The results of my tests are inconsistent. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C23 | The effectiveness of my treatment is undetermined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |

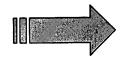
| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-----|--|----------------------|----------|-----------|-------|-------------------|--|
| C24 | It is difficult to determine how long it will be before I can care for myself. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C25 | I can generally predict the course of my illness. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C26 | Because of the treatment, what I can do and cannot do keeps changing. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C27 | I'm certain they will not find anything else wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C28 | The treatment I am receiving has a known probability of success. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C29 | They have not given me a specific diagnosis. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C30 | My physical distress is predictable; I know when it is going to get better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C31 | I can depend on the nurses to be there when I need them. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C32 | The seriousness of my illness has been determined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C33 | The doctors and nurses use everyday language so I can understand what they are saying. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |

Please continue to the next page of the questionnaire.



The following statements are about your sense of control over your life **since your diagnosis of prostate cancer**. Please circle the response that best describes how you think and feel since your diagnosis.

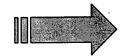
| | SENSE OF CONTROL | CIRCLE RESPONSE | | | | |
|----|--|----------------------|----------|-----------|-------|-------------------|
| | MPLE: Most of my problems due to bad breaks. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| D1 | There is no sense in planning a lot. If something is going to happen, it will. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| D2 | The really good things that happen to me are mostly luck. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| D3 | I am responsible for my own successes. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| D4 | I can do just about anything I really set my mind to. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| D5 | Most of my problems are due to bad breaks. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| D6 | I have little control over the bad things that happen to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| D7 | My misfortunes are a result of the mistakes I have made. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| D8 | I am responsible for my failures. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |



The next questions ask about marital attitudes and behaviors. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

| | ATTITUDES AND BEHAVIORS | CIRCLE RESPONSE | | | | | | | |
|--|--|---------------------------|----|---|----|------|-------------------|-----------|-------------------|
| Exa stro | mple: Our marriage is ng. | Strongly 1234 Disagree | | | 4 | -(-5 | Strongly Agree | | |
| E1 | We have a good marriage. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 67 | Strongly Agree |
| E2 | My relationship with my partner is very stable. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 7 | Strongly Agree |
| E3 | Our marriage is strong. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 7 | Strongly Agree |
| E4 | My relationship with my partner makes me happy. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 7 | Strongly Agree |
| E5 | I really feel like part of a team with my partner. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 7 | Strongly Agree |
| E6. On the scale below, indicate the point which best describes the degree of happiness, everything considered, in your marriage. Please circle the number that best represents your response. | | | | | | | | | |
| 1- | 34 | 5 | 6 | | 7- | | 8 | 9 | 10 |
| V | ery unhappy | Нарр | ру | | | | | Perfectly | happy |

17



In the space below, please answer the following questions.

| F1. Since your diagnosis of prostate cancer, what has your wife said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way? |
|---|
| |
| |
| |
| |
| |
| To O' what have you wished that your wife had done or said to |
| F2. Since your diagnosis of prostate cancer, what have you wished that your wife had done or said to help you cope with cancer that she did not do? |
| |
| |
| |
| |
| |
| |
| |

The statements below are possible reactions that you may have had towards your wife since your diagnosis of prostate cancer. Please tell us how often you have responded this way **since your diagnosis with prostate cancer**.

| | THOUGHTS AND FEELINGS | | CIRCLE | RESPONSE | |
|------------|---|--------------------------------|---------------------------------|------------------------------------|--------------------------------|
| | EXAMPLE: Since your diagnosis, you've seemed not to enjoy being around her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G1 | Since your diagnosis, you've acted impatient with her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G2 | Since your diagnosis, you've seemed angry or upset with her when she needed assistance. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G3 | Since your diagnosis you've complimented the way she was coping with your illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G4 | Since your diagnosis, you've seemed not to enjoy being around her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G 5 | Since your diagnosis, you've made her wait a long time for help when she needed it. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G6 | Since your diagnosis, you've made it comfortable for her to share with you how she was feeling. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G 7 | Since your diagnosis, you've avoided being around her when she was not feeling well. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G8 | Since your diagnosis, you've given her the idea you really did not want to talk about a problem she was having. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |

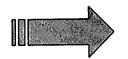
| , | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | | |
|-----|---|--------------------------------|---------------------------------|------------------------------------|--------------------------------|--|--|--|
| G9 | Since your diagnosis, you've shouted or yelled at her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | | |
| G10 | Since your diagnosis, you have made it a point to spend time with her when you thought she was feeling low. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | | |
| G11 | Since your diagnosis, you've not seemed to respect her feelings. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | | |
| G12 | Since your diagnosis, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | | |
| G13 | Since your diagnosis, you've acted uncomfortable talking to her about how she was coping with your illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | | |
| G14 | Since your diagnosis, you've criticized the way she was coping with your disease and/or its treatment. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | | |
| G15 | Since your diagnosis, you have been affectionate with her when you thought she needed support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | | |
| G16 | Since your diagnosis, you've acted less accepting of her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | | |
| G17 | Since your diagnosis, you've not been emotionally supportive of her when she expected some support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | | |

The next questions concern your relationship with your wife <u>since your</u> <u>diagnosis of prostate cancer.</u> Please circle the response that best describes your thoughts and feelings about each statement.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | | |
|-----|--|----------------------|----------|-------|-------------------|---|--|--|
| hav | AMPLE: Since my diagnosis, I e not been able to turn to my e for guidance in times of ess. | Strongly Disagree | Disagree | Agree | Strongly | | | |
| H1 | Since my diagnosis, I have been able to depend on my wife to help me if I really need it. | Strongly Disagree | Disagree | Agree | Strongly Agree | | | |
| H2 | Since my diagnosis, I have not been able to turn to my wife for guidance in times of stress. | Strongly Disagree | Disagree | Agree | Strongly Agree | | | |
| Н3 | Since my diagnosis, my wife has enjoyed the same social activities I do. | Strongly Disagree | Disagree | Agree | Strongly Agree | | | |
| H4 | Since my diagnosis, I have felt personally responsible for my wife's well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | | | |
| H5 | Since my diagnosis, I have not thought that my wife respected my skills and abilities. | Strongly Disagree | Disagree | Agree | Strongly Agree | | | |
| Н6 | Since my diagnosis, if something went wrong my wife would not come to my assistance. | Strongly Disagree | Disagree | Agree | Strongly Agree | · | | |
| H7 | Since my diagnosis, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | | | |
| Н8 | Since my diagnosis, my wife has recognized my competence and skill. | Strongly Disagree | Disagree | Agree | Strongly Agree | | | |
| Н9 | Since my diagnosis, my wife has not shared my interests and concerns. | Strongly Disagree | Disagree | Agree | Strongly Agree | | | |

| | THOUGHTS AND FEELINGS | | CIRCLE | RESPON | ISE | |
|-----|---|----------------------|----------|--------|-------------------|--|
| H10 | Since my diagnosis, my wife has not really relied on me for her well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H11 | Since my diagnosis, my wife has been a trustworthy person I could turn to for advice if I were having problems. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H12 | Since my diagnosis, I have lacked a feeling of intimacy with my wife. | Strongly Disagree | Disagree | Agree | Strongly Agree | |

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.

<u>Does your health now limit you in these activities?</u> If so, how much? Please circle your response.

| ACTIVITIES | CIRCLE RESPONSE | | | | | | |
|--|-----------------------|--------------------------|------------------------|--|--|--|--|
| EXAMPLE: Lifting or carrying groceries | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I1. Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I3. Lifting or carrying groceries | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I4. Climbing several flights of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I5. Climbing one flight of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I6. Bending, kneeling, or stooping | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I7. Walking more than a mile | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I8. Walking several blocks | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I9. Walking one block | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |
| I10. Bathing or dressing yourself | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | | |

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During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities <u>as a result of your **PHYSICAL**</u> **HEALTH**? Please circle YES or NO for each question.

| PROBLEMS AS A RESULT OF PHYSICAL HEALTH | CIRCLE RESPONSE | | | | |
|--|-----------------|----|--|--|--|
| EXAMPLE: Accomplished less than you would like | Yes | No | | | |
| I11. Cut down on the amount of time you spent on work or other activities | Yes | No | | | |
| I12. Accomplished less than you would like | Yes | No | | | |
| I13. Were limited in the kind of work or other activities | Yes | No | | | |
| I14. Had difficulty performing the work or other activities (for example, it took extra effort) | Yes | No | | | |

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities <u>as a result of any **EMOTIONAL PROBLEMS**</u>, such as feeling depressed or anxious? Please circle YES or NO for each question.

| EMOTIONAL PROBLEMS | CIRCLE RESPONSE | | | |
|--|-----------------|----|--|--|
| I15. Cut down on the amount of time you spent on work or other activities | Yes | No | | |
| I16. Accomplished less than you would like | Yes | No | | |
| I17. Didn't do work or other activities as carefully as usual | Yes | No | | |

These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks ...

| | FEELINGS | CIRCLE RESPONSE | | | | | | | |
|---|---|--------------------|------------------|------------------------------|------------------------|----------------------|------------------|--|--|
| EXAMPLE: Have you felt calm and peaceful? | | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I18. | Did you feel full of pep? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I19. | Have you been a very nervous person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| 120. | Have you felt so down in the dumps that nothing could cheer you up? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I21. | Have you felt calm and peaceful? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I22 | Did you have a lot of energy? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I23. | Have you felt downhearted and blue? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I24. | Did you feel worn out? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I25. | Have you been a happy person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I26. | Did you feel tired? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |

| veeks, to what r normal social esponse2Slightly vain have you had the social esponse. | extent has your physic activities with family, f 3 Moderately ad during the past 4 v -34 Mild Mode | A little of the time cal health or emotional riends, neighbors, or grand Quite a bit weeks? Please circle years arate Severe | the time problems oups?5 Extremely our response. |
|--|--|---|--|
| r normal social esponse2 | activities with family, f 3 Moderately nad during the past 4 v -34 Mild Mode | riends, neighbors, or gr Quite a bit Weeks? Please circle y | oups? Extremely our response. |
| Slightly pain have you have have have you have have you have have you have have you have have have have have have have have | Moderately nad during the past 4 v -34 Mild Mode | Quite a bit weeks? Please circle y | Extremely our response. |
| nild I | -34 Mild Mode | 5 | 6 |
| veeks, how mu | ab did nair interfere w | | |
| 2 | ? Please circle your re 3 | 4 | 5 |
| Slightly ———— | Moderately | Quite a bit | Extremely |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | 24 |

Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

| | CIRCLE RESPONSE | | | | NSE | | | | | |
|---|---------------------|-------------------------|-----------------|-----------------|-------------------------|---------------------------------------|-----------|-------------------|-------------------------------------|--|
| EXAMPLE: I expect my health to get worse. | | Definitely Mostly true. | | N | Not sure. Mostly false. | | | Definitely false. | | |
| I31. I seem to get sic easier than other | Defini true | - 1 | Mostly true. | | lot sure. | Mostly fa | alse. | Definitely false. | | |
| I32. I am as healthy a anyone I know. | Definitely true. | | Mostly true. | Not sure. | | Mostly fa | alse. | Definitely false. | | |
| I33. I expect my heal worse. | Definitely true. | | Mostly true. | Not sure. | | Mostly false. | | Definitely false. | | |
| I34. My health is exc | ellent. | Definitely true. | | Mostly true. | | lot sure. | Mostly fa | alse. | Definitely false. | |
| I35. In general, would you say your health is: Please circle your response. | | | | | | | | | | |
| Excellent | Very (| Good | | Good | | F | air | | Poor | |
| I36. Compared to one year ago, how would you rate your health in general now? Please circle your response. | | | | | | | | | | |
| Much better now than one year ago. Somewhat better now than one year ago. | | | Abo | About the same. | | Somewhat worse now than one year ago. | | | ch worse now an one year ago. | |

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

| J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response. | | | | | | | | | |
|---|---|-------------|----------|------------------------|----------------------------|--------|-----------------------------------|----------------|--|
| Every day | About once a week. | | | Less than once a week. | | | Not at all. | | |
| J2. Which of the following best describes your urinary control during the last 4 weeks? Please circle your response. | | | | | | | | | |
| No control whatsoever. | * · · · · · · · · · · · · · · · · · · · | | | | ing. Occasional dribbling. | | | Total control. | |
| J3. How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks? Please circle your response. | | | | | | | | | |
| 3 or more pads per | day. | 1- | -2 pads | per day. | | | No pads. | | |
| How big a problem, if a | any, has | each of the | followir | ng been f | or you? | Please | circle your res | sponse. | |
| J4. Dripping urine or wetting your pants. No problem Very small Small Moderate problem problem problem problem | | | | | Big problem | | | | |
| J5. Urine leakage No problem Very small Small Moderate Big problem problem problem problem | | | | | | | | | |
| J6. Overall, how big a problem has your urinary function been for you during the last 4 weeks? Please circle your response. | | | | | | | | | |
| 12 | | | | nall Mode | | | 45 derate Big oblem problem | | |

BOWEL HABITS: This section is about your bowel habits and abdominal pain. Please consider **ONLY THE LAST 4 WEEKS**.

| | have you had rec ks? Please circle | | ke you had to | pass stool, but did n | ot) during the |
|----------------------------|--|--|----------------------------------|------------------------------|---|
| 1 | 2 | 3 | | 4 | 5 |
| | | | n once | About once a week | |
| J8. How often mushy) du | have you had sto ring the last 4 we | ols (bowel moven eks? Please circle | nents) that were your respons | re loose or liquid (no e. | form, watery, |
| 1 | 2 | 3 | | 4 | 5 |
| Never | Rarely | About I the tir | half | Usually | Always |
| Please ci | rcle your respons Mo | e. | | | *************************************** |
| | n have you had cr rcle your respons | | r abdomen or | pelvis during the las | t 4 weeks? |
| 1 | 2 | 3 | 4 | 5 | 6 |
| | | | | About once | |
| Times a day | a day | times a week | a week | this month | or never |
| | low big a problem rcle your respons | | nabits been for | you during the last | 4 weeks? |
| 1 | | 3 | | 4 | 5 |
| | | Smal | 1 | Very small | No |
| ~ | problem | proble | em | problem | problem |

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY. Please answer honestly about **THE LAST 4 WEEKS ONLY**.

| How has ead | ch of the fo | llowing bee | n for y | ou? Pleas | se circle | your | response. | | |
|---|--|--|----------|------------------------------|-----------|--------|--------------------------------------|------------------|---|
| • | 2. Your level of Very p sexual desire? | | oor | r Poor | | | Fair | Good | Very good |
| J13. Your ab have an | ility to erection? | Very p | oor | Pod | or | | Fair | Good | Very good |
| J14. Your ability to reach orgasm (climax)? | | Very p | y poor | | Poor | | Fair | Good | Very good |
| J15. How wo None at | | Not firm e | ····· | for any | Fir | m en | ons? Please ough for ation and | Firn | ur response. n enough for tercourse. |
| J16. How wo | uld you de | | | | fo | repla | ns? Please c | | |
| I NEVER ha erection who wanted on | en I LE | nad an erec SS THAN H e time I war one. | IALF | I had a ABOUT time I w | | the | I had an e MORE THA the time I | N HALF wanted | I had an erection WHENEVER I wanted one. |
| J17. How ofto respons | | u awakene | d in the | e morning | or nigh | t with | an erection | ? Please | circle your |
| Never | 1 | (less than the time) | | often (less alf the tim | | | en (more that alf the time). | } | ery often (more an 75% of the time) |

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| J18. During the I | ast 4 weeks, did you | have vaginal or anal inter | course? Please circle | your response. |
|--|---|--|---|--|
| No | | Yes, once | Yes, more | than once |
| J19. Overall, hov | | r ability to function sexual | ly during the last 4 we | eks? Please |
| 1 | 22 | 3 | 4 | 5 |
| /ery poor | Poor | 3 Fair | Good | Very good |
| | w big a problem has y le your response. | your sexual function been | | , |
| 1 | 2 | 3 | 4 | 5 |
| No | Very | 3 Small | Moderate | Big |
| No Problem | Very small problem | Small problem | Moderate problem | Big problem |
| No Problem J21. Overall, hove circle your in the second control of the second control o | Very small problem w satisfied are you wiresponse. | Small problem ith the treatment you rece | Moderate problem ived for your prostate | Big problem cancer? Please |
| No Problem J21. Overall, how circle your in the street that t | Very small problem w satisfied are you wiresponse. Dissatisfied | Small problem ith the treatment you recei | Moderate problem ived for your prostate Satisfied | Big problem cancer? Please 5 Extremely |
| No Problem J21. Overall, how circle your in the street that t | Very small problem w satisfied are you wiresponse. Dissatisfied | Small problem ith the treatment you receive and the streatment with the treatment you receive and the streatment with the treatment you receive and the streatment with the streatment you receive and the streatment with the streatment you receive and the streatment with the streatment with the streatment you receive and the streatment with the streatment you receive and | Moderate problem ived for your prostate Satisfied | Big problem cancer? Please 5 Extremely |
| No Problem J21. Overall, how circle your in the second se | Very small problem w satisfied are you wiresponse. Dissatisfied ections require chemi | Small problem ith the treatment you receive and the streatment with the treatment you receive and the streatment with the treatment you receive and the streatment with the streatment you receive and the streatment with the streatment you receive and the streatment with the streatment with the streatment you receive and the streatment with the streatment you receive and | Moderate problem ived for your prostate Satisfied | Big problem cancer? Please 5 Extremely |
| No Problem J21. Overall, how circle your in the second se | Very small problem w satisfied are you wiresponse. Dissatisfied ections require chemi | Small problem ith the treatment you receive and assistance? Please makes which method you use. | Moderate problem ived for your prostate Satisfied | Big problem cancer? Please 5 Extremely |
| No Problem J21. Overall, how circle your in the second se | Very small problem w satisfied are you wiresponse. Dissatisfied ections require chemicate f yes, please indicate Viagra Injections | Small problem ith the treatment you receive the second se | Moderate problem ived for your prostate Satisfied | Big problem cancer? Please 5 Extremely |

Please answer the following questions related to your prostate cancer diagnosis.

| K1. When did you first hear of the Prostate Specific Antigen (PSA) test or prostate blood test? 1 I have never heard of the PSA test. 2 I heard about it from the media (T.V., radio, newspaper, magazine). 3 I heard about it from my spouse. 4 I heard about it from my friends or relatives. 5 I heard about it from my primary care physician. 6 I heard about it from my urologist. 7 I heard about it today while in the clinic. | | | | | | | | |
|--|--|-------------------------|-------------|-----------------|--|--|--|--|
| circle you | K2. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response. 13 | | | | | | | |
| None | A little | A moderate amount | A lot | A great deal | | | | |
| 1 No (go 2 Yes (g | K3. Has a doctor ever talked to you about your PSA level? Please mark your response. 1 No (go to question K5). 2 Yes (go to question K4). 3 Don't know (go to question K5). | | | | | | | |
| K4. How satisfied were you with the discussion that you had with your doctor about your PSA Level? Please circle your response. | | | | | | | | |
| Not at all | Slightly | Moderately satisfied | Quite a lot | Completely | | | | |
| K5. Do you kı | now your last PSA val | ue? | | | | | | |
| 1 YES | YES If Yes, please write it here: PSA value (ng/ml) | | | | | | | |
| 2 NO | 2 NO If No, please mark one of the following options: | | | | | | | |
| | 2a I don't | remember my last PSA | value. | | | | | |
| | 2b I have never been told my PSA value. | | | | | | | |

| K6. Do yo | u know what d | ifferent PSA lev | vels mean? Pleas | e mark your re | sponse. | |
|------------------------|------------------|---------------------|---------------------------------------|------------------|---------|---|
| 1 No. 2 You 3 U | es | | | | | |
| or hig | h? Please circ | le your respons | | | | |
| 1 | | 2 | 3 | 4 | | 5 |
| Not at all Concerne | d co | Slightly ncerned | Moderately concerned | Quite concern | ed | concerned |
| treatn | | | out how your PSA se mark your resp | | | |
| treatn | nent? Please o | circle your respo | | | | *************************************** |
| No | Very unlikely | Unlikely | 4 Moderate chance | Likely | Verv | Certain to happen |
| Did any No | | | letion of this ques | tionnaire? | | |
| Yes | If yes | , who? | | | | |

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the second questionnaire one month after you begin your treatment for prostate cancer.

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Spouse Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage paid envelope before your spouse's treatment for prostate cancer begins.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your husband, and views of your husband's illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

| | UND INFORMA | ATION - PLEASE | E PRINT. |
|--|--------------------|----------------------|----------|
| Today's date:/// | / / Year | | |
| Name: | · | | - |
| Home Address: | Street | | Apt. # |
| City | State | Zip Code | |
| Home Phone Number: () | | | |
| Date of Birth:// | / Year | | |
| What is your highest level of e | ducation? (Put a | checkmark by the a | nswer.) |
| Grade school Some high school High school graduate Some college College graduate |) | | |
| 6 Graduate education | | | |
| | scribes your racia | l or ethnic backgroւ | ınd? |

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| A8. | Which of the following best describes your current relationship? |
|----------------------------|--|
| | Living with spouse or partner In a significant relationship, but not living together Not in a significant relationship |
| A9. | What is your current marital status? |
| | 1 Never married 2 Married 3 Separated 4 Divorced 5 Widowed |
| A10. | How long have you been married/separated/divorced/widowed? years |
| A11. | Who else lives in your household besides yourself? (Please check all that apply.) |
| | 1Your husband/wife 2Your mother 3Your father 4Your children 18 or under — How many? 5Your children over 18 — How many? 6Sister(s) — How many? 7Brother(s) — How many? 8Grandchildren — How many? 9Grandparent(s) — How many? 10Other relatives — How many? 11Other non-relatives — How many? 12I live by myself. |
| A12. | Here are several broad income ranges. Please select the range that most closely approximates <u>your</u> yearly household income, before taxes, from all sources, including social security. |
| 2 3 4 5 6 7 | 0 - \$4,000 \$4,001 - \$9,000 \$18,001 - \$18,000 \$30,001 - \$40,000 \$40,001 - \$50,000 \$50,001 - \$60,000 Above \$60,000 |
| A13. | Altogether, how many people live on this income? |
| | People. |

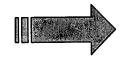
Do you have any of the following illnesses or conditions at the present time?

| | ILLNESS / CONDITION | | | | how much the illness th your daily activities. | | |
|-----|--|----|-----|------------|---|--------------|--|
| Exa | mple: Asthma | No | Yes | Not At All | A Little | A Great Deal | |
| B1 | Anemia | No | Yes | Not At All | A Little | A Great Deal | |
| B2 | Arthritis or rheumatism | No | Yes | Not At All | A Little | A Great Deal | |
| В3 | Asthma | No | Yes | Not At All | A Little | A Great Deal | |
| B4 | Cancer or leukemia | No | Yes | Not At All | A Little | A Great Deal | |
| B5 | Circulation trouble in arms, legs, or feet | No | Yes | Not At All | A Little | A Great Deal | |
| B6 | Depression, anxiety or emotional problems | No | Yes | Not At All | A Little | A Great Deal | |
| В7 | Diabetes | No | Yes | Not At All | A Little | A Great Deal | |
| В8 | Effects of Polio | No | Yes | Not At All | A Little | A Great Deal | |
| В9 | Effects of stroke | No | Yes | Not At All | A Little | A Great Deal | |
| B10 | Emphysema or chronic bronchitis | No | Yes | Not At All | A Little | A Great Deal | |
| B11 | Epilepsy/seizures | No | Yes | Not At All | A Little | A Great Deal | |
| B12 | Glaucoma | No | Yes | Not At All | A Little | A Great Deal | |
| B13 | Heart Disease | No | Yes | Not At All | A Little | A Great Deal | |
| B14 | High blood pressure (greater than 140/90) | No | Yes | Not At All | A Little | A Great Deal | |
| B15 | Kidney disease | No | Yes | Not At All | A Little | A Great Deal | |
| B16 | Liver disease | No | Yes | Not At All | A Little | A Great Deal | |
| B17 | Multiple Sclerosis | No | Yes | Not At All | A Little | A Great Deal | |

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| | ILLNESS / CONDITION | 1 | e No or 'es | If YES, circle how much the illness interferes with your daily activities. | | | |
|-----|---|----|----------------|--|----------|--------------|--|
| B18 | Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome | No | Yes | Not At All | A Little | A Great Deal | |
| B19 | Other urinary tract disorders (including prostate trouble) | No | Yes | Not At All | A Little | A Great Deal | |
| B20 | Parkinson's Disease | No | Yes | Not At All | A Little | A Great Deal | |
| B21 | Severe memory problems such as Alzheimer's or other dementing illness | No | Yes | Not At All | A Little | A Great Deal | |
| B22 | Skin disorders such as pressure sores, leg ulcers, or severe burns. | No | Yes | Not At All | A Little | A Great Deal | |
| B23 | Thyroid or other glandular disorders | No | Yes | Not At All | A Little | A Great Deal | |
| B24 | Tuberculosis | No | Yes | Not at All | A Little | A Great Deal | |
| B25 | Stomach Ulcers | No | Yes | Not at All | A Little | A Great Deal | |
| B26 | Leg Amputation(s) | No | Yes | Not at All | A Little | A Great Deal | |

Please continue to the next page of the questionnaire.



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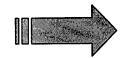
The following statements are about your thoughts and feelings <u>since your</u> <u>husband was diagnosed with prostate cancer.</u> Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | |
|-------|--|----------------------|----------|-----------|-------|-------------------|
| treat | MPLE: The purpose of each ment for my husband is to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C1 | I do not know what is wrong with my husband. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C2 | I have a lot of questions without answers. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C3 | I am unsure if my husband's illness is getting better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C4 | It is unclear how bad my husband's pain will be. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C5 | The explanations they give about my husband's condition seem hazy to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C6 | The purpose of each treatment for my husband is clear to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C7 | I do not know when to expect things will be done to my husband. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C8 | My husband's symptoms continue to change unpredictably. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| С9 | I understand everything explained to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C10 | The doctors say things to me that could have many meanings. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |

| , • | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | |
|-----|--|----------------------|----------|-----------|-------|-------------------|
| C11 | I can predict how long my husband's illness will last. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C12 | My husband's treatment is too complex to figure out. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C13 | It is difficult to know if the treatments or medications my husband is getting are helping. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C14 | There are so many different types of staff, it is unclear who is responsible for what. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C15 | Because of the unpredictability of my husband's illness, I cannot plan for the future. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C16 | The course of my husband's illness keeps changing. He has good days and bad days. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C17 | It's vague to me how I will manage my husband's care after he leaves the hospital. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C18 | It is not clear what is going to happen to my husband. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C19 | I usually know if my husband is going to have a good or bad day. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C20 | The results of my husband's tests are inconsistent. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C21 | The effectiveness of my husband's treatment is undetermined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C22 | It is difficult to determine how long it will be before I can care for my husband by myself. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C23 | I can generally predict the course of my husband's illness. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |

| | THOUGHTS AND FEELINGS | | С | IRCLE RESP | ONSE | ı f |
|-----|--|----------------------|----------|------------|-------|-------------------|
| C24 | Because of the treatment, what my husband can do and cannot do keeps changing. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C25 | I am certain they will not find anything else wrong with my husband. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C26 | They have not given my husband a specific diagnosis. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C27 | My husband's physical distress is predictable; I know when it is going to get better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C28 | My husband's diagnosis is definite and will not change. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C29 | I can depend on the nurses to be there when I need them. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C30 | The seriousness of my husband's illness has been determined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C31 | The doctors and nurses use everyday language so I can understand what they are saying. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |

Please continue to the next page of the questionnaire.



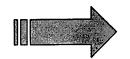
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The following statements are about your sense of control over your life <u>since</u> <u>your husband's prostate cancer diagnosis.</u> Please circle the response that best describes how you think and feel about each statement.

| | SENSE OF CONTROL CIRCLE RESPONSE | | | | | | |
|--------------------|--|----------------------|----------|-----------|-------|-------------------|--|
| W-3/98003888800000 | mple: Most of my problems due to bad breaks. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| D1 | There is no sense in planning a lot. If something is going to happen, it will. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | and the second s |
| D2 | The really good things that happen to me are mostly luck. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| D3 | I am responsible for my own successes. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| D4 | I can do just about anything I really set my mind to. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | neere landes de cocaman annere de servas annere de la cocama |
| D5 | Most of my problems are due to bad breaks. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| D6 | I have little control over the bad things that happen to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| D7 | My misfortunes are a result of the mistakes I have made. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| D8 | I am responsible for my failures. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |

The next questions ask about marital attitudes and behaviors. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. Please answer the questions without talking to your partner. Your partner should not see or help with the answers. Circle the number from 1 to 7 that best describes your thoughts and feelings about each statement.

| | ATTITUDES AND BEHAVIORS | CIRCLE RESPONSE | | |
|-------------|---|--|-------------------|--|
| Exa stro | mple: Our marriage is ng. | Strongly 1234567 Disagree | Strongly Agree | |
| E1 | We have a good marriage. | Strongly 13567 S Disagree | trongly Agree | |
| E2 | My relationship with my partner is very stable. | Strongly 13567 Si Disagree | trongly Agree | |
| E3 | Our marriage is strong. | Strongly 1 3 5 S Disagree | trongly Agree | |
| E4 | My relationship with my partner makes me happy. | Strongly 1 3 5 5 S Disagree | trongly Agree | |
| E5 | I really feel like part of a team with my partner. | Strongly 13567 S Disagree | trongly Agree | |
| | n the scale below, circle the number rthing considered, in your marriage. | rom 1-10 that best describes the degree of happine | ss, | |
| 1- | 34 | 599 | 10 | |
| Ve | ery unhappy | Happy Perfectly h | арру | |



In the space below, please answer the following questions.

| | í |
|--|--|
| F1. Since your husband's diagnosis of prostate cancer, what has your husband said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way? | |
| | |
| | |
| | |
| | |
| | *************************************** |
| | addamentalconnentamentamentopologic |
| F2. Since your husband's diagnosis of prostate cancer, what have you wished that your husband ha done or said to help you cope with his cancer that he did not do? | d |
| | - Andrewski se |
| | |
| | |
| | |
| | |
| | |
| | |

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The statements below are possible reactions that you may have had towards your husband since his diagnosis of prostate cancer. Please tell us how often you have responded this way **since his diagnosis**.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | |
|-----------|--|--------------------------------|---------------------------------|------------------------------------|--------------------------------|--|
| | EXAMPLE: Since your husband's diagnosis, you seemed not to enjoy being around him. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G1 | Since your husband's diagnosis, you've acted impatient with him. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G2 | Since your husband's diagnosis, you've seemed angry or upset with him when he needed assistance. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G3 | Since your husband's diagnosis, you've complimented the way he was coping with his illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G4 | Since your husband's diagnosis, you've seemed not to enjoy being around him. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G5 | Since your husband's diagnosis, you've made him wait a long time for help when he needed it. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G6 | Since your husband's diagnosis, you've made it comfortable for him to share with you how he was feeling. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G7 | Since your husband's diagnosis, you've avoided being around him when he was not feeling well. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |

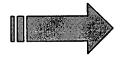
| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | |
|------------|---|--------------------------------|---------------------------------|------------------------------------|--------------------------------|--|
| G8 | Since your husband's diagnosis, you've given him the idea you really did not want to talk about a problem he was having. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G 9 | Since your husband's diagnosis, you've shouted or yelled at him. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G10 | Since your husband's diagnosis, you've made it a point to spend time with him when you thought he was feeling low. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G11 | Since your husband's diagnosis, you haven't seemed to respect his feelings. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G12 | Since your husband's diagnosis, you've complained about his illness or about helping him with a task he found difficult to do by himself. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G13 | Since your husband's diagnosis, you've acted uncomfortable talking to him about his illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G14 | Since your husband's diagnosis, you've criticized the way he was coping with his disease and/or its treatment. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G15 | Since your husband's diagnosis, you've been affectionate with him when you thought he needed support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G16 | Since your husband's diagnosis, you've acted less accepting of him. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |
| G17 | Since your husband's diagnosis, you haven't been emotionally supportive of him when he expected some support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | |

The next set of questions concern your relationship with your husband <u>since</u> <u>his diagnosis of prostate cancer</u>. Please circle the response that best describes your thoughts and feelings about each statement.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | |
|--------------------------|--|----------------------|----------|-------|-------------------|--|
| 24.7555,4000000000000000 | mple: My husband does not w me as competent. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H1 | Since my husband's diagnosis, I have been able to depend on him to help me if I really need it. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H2 | Since my husband's diagnosis, I have not been able to turn to him for guidance in times of stress. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| Н3 | Since my husband's diagnosis, he has enjoyed the same social activities I do. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H4 | Since my husband's diagnosis, I have felt personally responsible for his well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H5 | Since my husband's diagnosis, I have not thought that he respected my skills and abilities. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| Н6 | Since my husband's diagnosis, if something went wrong he would not come to my assistance. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H7 | Since my husband's diagnosis, I have had a close relationship with him that provides me with a sense of emotional security and well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H8 | Since my husband's diagnosis, he has recognized my competence and skill. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| Н9 | Since my husband's diagnosis, he has not shared my interests and concerns. | Strongly Disagree | Disagree | Agree | Strongly Agree | |

| | THOUGHTS AND FEELINGS | | CIRCLE | RESPON | ISE |
|-----|--|----------------------|----------|--------|-------------------|
| H10 | Since my husband's diagnosis, he has not really relied on me for his well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H11 | Since my husband's diagnosis, he has been a trustworthy person I could turn to for advice if I were having problems. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H12 | Since my husband's diagnosis, I have lacked a feeling of intimacy with him. | Strongly Disagree | Disagree | Agree | Strongly Agree |

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.

<u>Does your health now limit you in these activities?</u> If so, how much? Please circle your response.

| ACTIVITIES | CIRCLE RESPONSE | | | | | |
|--|-----------------------|--------------------------|------------------------|--|--|--|
| EXAMPLE: Lifting or carrying groceries | Yes, limited a lot | Yes, limited a | No, not limited at all | | | |
| I1. Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I3. Lifting or carrying groceries | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I4. Climbing several flights of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I5. Climbing one flight of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I6. Bending, kneeling, or stooping | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I7. Walking more than a mile | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I8. Walking several blocks | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I9. Walking one block | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I10. Bathing or dressing yourself | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities <u>as a result of your **PHYSICAL**</u> **HEALTH**? Please circle YES or NO for each question.

| PROBLEMS AS A RESULT OF PHYSICAL HEALTH | CIRCLE RESPONSE | | | |
|--|-----------------|----|--|--|
| EXAMPLE: Accomplished less than you would like | Yes | No | | |
| I11. Cut down on the amount of time you spent on work or other activities | Yes | No | | |
| I12. Accomplished less than you would like | Yes | No | | |
| I13. Were limited in the kind of work or other activities | Yes | No | | |
| I14. Had difficulty performing the work or other activities (for example, it took extra effort) | Yes | No | | |

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities <u>as a result of any **EMOTIONAL PROBLEMS**</u>, such as feeling depressed or anxious? Please circle YES or NO for each question.

| EMOTIONAL PROBLEMS | CIRCI | E RESPONSE | |
|--|-------|------------|--|
| I15. Cut down on the amount of time you spent on work or other activities | Yes | No | |
| I16. Accomplished less than you would like | Yes | No | |
| I17. Didn't do work or other activities as carefully as usual | Yes | No | |

These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks ...

| | FEELINGS | CIRCLE RESPONSE | | | | | | | |
|------|---|-----------------|---------------------|------------------------------|------------------|----------------------|---------------------|--|--|
| | AMPLE: Have you felt calm and peaceful? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I18. | Did you feel full of pep? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I19. | Have you been a very nervous person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I20. | Have you felt so down in the dumps that nothing could cheer you up? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I21. | Have you felt calm and peaceful? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I22 | Did you have a lot of energy? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I23. | Have you felt downhearted and blue? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I24. | Did you feel worn out? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I25. | Have you been a happy person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I26. | Did you feel tired? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |

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| interfere | he past 4 weeks , how m d with your social activition ircle your response. | uch of the time has you es (like visiting with frier | r physical health or emonds, relatives, etc.)? | otional problems |
|-----------------|---|---|---|--------------------------|
| | 2Most of the time | 3 Some of the time | A little of the time | 5 None of the time |
| interfere | he past 4 weeks , to wha ed with your normal socia circle your response. | it extent has your physic al activities with family, f | cal health or emotional priends, neighbors, or gr | problems oups? |
| 1 | 22 | 3 | 4 | 5 |
| Not at all | Slightly | Moderately | Quite a bit | Extremely |
| 1 | ch bodily pain have you 2 Very mild | 34 | 5 | 6 |
| outside t | he past 4 weeks , how m the home and housework | k)? Please circle your re | esponse. | |
| 1 Not at all | 2 Slightly | 3 Moderately | Quite a bit | Extremely |
| | | | | |
| | | | | |

Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

| STATEMENT | | | | | | CIRCLE RESPONSE | | | | |
|---|-----------|-------------------------|--------------|-------------------|-----------|-------------------------------------|-----------------|-------------------|-------------------|--|
| EXAMPLE: I expect my health to get worse. | | Definitely Mostly true. | | No | ot sure. | t sure. Mostly false. | | Definitely false. | | |
| I31. I seem to get sick a little easier than other people. | | Definitely true. | | Mostly true. | N | lot sure. | Mostly fa | alse. | Definitely false. | |
| I32. I am as healthy a anyone I know. | as | Defini true | • | Mostly true. | N | lot sure. | Mostly false. | | Definitely false. | |
| I33. I expect my heal worse. | th to get | Defini true | - | Mostly true. | N | lot sure. | ure. Mostly fal | | Definitely false. | |
| I34. My health is exc | ellent. | Defini true | • | Mostly true. | N | lot sure. | Mostly false. | | Definitely false. | |
| I35. In general, would Please circle you | - | | Ith is: | | | | | | | |
| Excellent | Very (| Good | | Good | Fair Poor | | | Poor | | |
| I36. Compared to one year ago, how would you rate your health in general now? Please circle your response. | | | | | | | | | | |
| Much better now than one year ago. Much better now better now than one year ago. | | Abo | ut the same. | now than one than | | ch worse now an one year ago. | | | | |

cancer diagnosis. K1. When did you first hear of the Prostate Specific Antigen (PSA) test or prostate blood test? 1. ___ I have never heard of the PSA test. 2. ___ I heard about it from the media (T.V., radio, newspaper, magazine). 3. ___ I heard about it from my husband. 4. ___ I heard about it from my friends or relatives. 5. ___ I heard about it from my primary care physician. 6. ___ I heard about it from my husband's `urologist. 7. I heard about it today while in the clinic. K2. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response. A lot A moderate A great A little None deal amount K3. Has a doctor ever talked to you about your husband's PSA level? Please mark your response. 1. ___ No (go to question K5). 2. Yes (go to question K4). 3. Don't know (go to question K5). K4. How satisfied were you with the discussion that you had with your husband's doctor about his PSA level? Please circle your response. Slightly Moderately Quite a lot Completely satisfied satisfied satisfied satisfied Not at all Satisfied K5. Do you know your husband's last PSA value? 1. ____ YES If Yes, please write it here: ____ PSA value (ng/ml) If No, please mark one of the following options: 2. NO 2a. I don't remember his last PSA value. 2b. _____ I have never been told my husband's PSA value.

Please answer the following questions related to your husband's prostate

| K6. Do you know what different PSA levels mean? Please mark your response. | | | | | | | | | |
|--|-------------------------------|-------------------------------------|--|------------------|---------------------------------------|----------------------|--|--|--|
| 1 No 2 Ye 3 Ur | es esure | | , | | | | | | |
| K7. How c | oncerned wer ed or high? P | e you when you lease circle you | ur doctor first tol ir response. | d your husban | d that his P | SA level was | | | |
| 1 | | 2 | 3 | 4 | | 5 | | | |
| Not at all | i co | Slightly | Moderately concerned | Quite | | Extremely | | | |
| K8. Has a his tre 1 No 2 Ye 3 Do | atment of pro | ilked to you abo state cancer? F | out how your hust Please mark your | oand's PSA lever | el will be use | ed to follow | | | |
| after his tre | eatment? Plea | ase circle your r | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | | |
| No | Very unlikely | Unlikely | Moderate chance | Likely | Very | Certain to happen | | | |
| Did anyo | one assist you | ı with the comp | letion of this ques | stionnaire? | | | | | |
| Me | | | | | | | | | |
| No Yes | If yes | s, who? | | | · · · · · · · · · · · · · · · · · · · | | | | |

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Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the second questionnaire one month after your spouse begins his treatment for prostate cancer.

Appendix C One Month Questionnaire

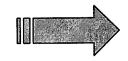
WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your spouse, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

| | GENERAL BACKGROUND | INFORMATIC | N - PLEASE P | RINT. |
|-----|-----------------------|------------|--------------|--------|
| A1. | Today's date:// | / Year | | |
| A2. | Name: | | | |
| A3. | Home Address: | Street | | Apt. # |
| | City | State | Zip Code | |
| A4. | Home Phone Number: () | | | |



PT/SF1

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The following statements are about your thoughts and feelings **since beginning your treatment for and/or management of prostate cancer.** Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | | | |
|--|---|----------------------|----------|-------------|-------|-------------------|--|--|--|
| EXAMPLE: The purpose of each treatment is clear to me. | | Strongly Disagree | Disagree | Undecided (| Agree | Strongly Agree | | | |
| C1 | I do not know what is wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C2 | I have a lot of questions without answers. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| С3 | I am unsure if my illness is getting better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C4 | It is unclear how bad my incontinence will be. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C5 | The explanations they give about my condition seem hazy to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C6 | The purpose of each treatment is clear to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C7 | When I have impotence, I know what this means about my condition. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C8 | I do not know when to expect things will be done to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C9 | My symptoms/side effects continue to change unpredictably. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C10 | I understand everything explained to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C11 | The doctors say things to me that could have many meanings. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

| | THOUGHTS AND FEELINGS | | CIR | CLE RESPO | NSE | - |
|-----|--|----------------------|----------|-----------|-------|-------------------|
| C12 | I can predict how long my illness will last. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C13 | My treatment is too complex to figure out. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C14 | It is difficult to know if the treatments or medications I am getting are helping. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C15 | There are so many different types of staff, it is unclear who is responsible for what. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C16 | Because of the unpredictability of my illness, I cannot plan for the future. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C17 | The course of my illness keeps changing. I have good days and bad days. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C18 | It is vague to me how I will manage my care now that I've left the hospital. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C19 | I have been given many differing opinions about what is wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C20 | It is not clear what is going to happen to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C21 | I usually know if I am going to have a good or bad day. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C22 | The results of my tests are inconsistent. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C23 | The effectiveness of my treatment is undetermined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

| ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,, | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | | |
|---|---|----------------------|----------|-----------|-------|-------------------|--|--|
| C24 | It is difficult to determine how long it will be before I can care for myself. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C25 | I can generally predict the course of my illness. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C26 | Because of the treatment's side effects, what I can do and cannot do keeps changing. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C27 | I am certain they will not find anything else wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C28 | The treatment I am receiving has a known probability of success. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C29 | They have not given me a specific diagnosis. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C30 | My incontinence and impotence are predictable; I know when they are going to get better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C31 | I can depend on the clinic staff to be there when I need them. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C32 | The seriousness of my illness has been determined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C33 | The doctors and nurses use everyday language so I can understand what they are saying. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |

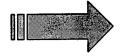
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The following statements are about your sense of control over your life <u>during</u> the past month. Please circle the response that best describes how you have thought and felt during the past four weeks.

| | SENSE OF CONTROL | CIRCLE RESPONSE | | | | | | |
|---|--|----------------------|----------|-----------|-------|-------------------|--|--|
| EXAMPLE: During the past month, most of my problems were due to bad breaks. | | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D1 | During the past month, there was no sense in planning a lot. If something is going to happen, it will. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D2 | During the past month, the really good things that happened to me were mostly luck. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D3 | During the past month, I was responsible for my own successes. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D4 | During the past month, I could do just about anything I really set my mind to. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D5 | During the past month, most of my problems were due to bad breaks. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D6 | During the past month, I had little control over the bad things that happened to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D7 | During the past month, my misfortunes were a result of the mistakes I made. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D8 | During the past month, I was responsible for my failures. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |

The next questions ask about marital attitudes and behaviors <u>during the past</u> <u>month.</u> Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions** without talking to your partner. Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

| ATTITUDES AND BEHAVIORS Example: During the past month, our marriage has been strong. | | CIRCLE RESPONSE | | | | | | |
|--|--|----------------------|-------|----|-------|------------|---------------------|--|
| | | Strongly Disagree | 12 | 3 | 4—(5- |) 6 7 | Strongly Agree | |
| E1 | During the past month, we have had a good marriage. | Strongly Disagree | 12 | 3 | -45 | 6 | 7 Strongly Agree | |
| E 2 | During the past month, my relationship with my partner has been very stable. | Strongly Disagree | 12 | 3 | -45 | 6 | 7 Strongly Agree | |
| E3 | During the past month, our marriage has been strong. | Strongly Disagree | 12 | 3 | -45 | 67 | Strongly Agree | |
| <u>E4</u> | During the past month, my relationship with my partner has made me happy. | Strongly Disagree | 12 | 3 | -45 | 67 | Strongly Agree | |
| E 5 | During the past month, I have really felt like part of a team with my partner. | Strongly Disagree | 12 | 3 | -45 | 67 | Strongly Agree | |
| ever | E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your marriage <u>during the past month</u> . Please circle the number that best represents your response. | | | | | | | |
| | 14 | 5 | 6 | 7- | 8- | . 9 | 10 | |
| , | Very unhappy | | Нарру | | | Perfec | Perfectly happy | |



In the space below, please answer the following questions.

| F1. During the past month, what has your wife said or done that you experienced as most annoy | |
|--|---|
| | ying or |
| That upset you, made you angry, or just somehow rubbed you the wrong way? | |
| That upset you, made you angry, or just somehow rubbed you the wrong way: | |
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| F2. During the past month, what have you wished that your wife had done or said to help you co | ope |
| with recovering from cancer that she did not do? | |
| with recovering from cancer that she did not do. | |
| | and a second |
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The statements below are possible reactions that you may have had towards your wife. Please tell us how often you have responded this way **during the past month**.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|------------------|--|--------------------------------|---------------------------------|------------------------------------|--------------------------------|--|--|
| 2.004 (1.004) | EXAMPLE: During the past month, you've seemed not to enjoy being around her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G1 | During the past month, you've acted impatient with her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G2 | During the past month, you've seemed angry or upset with her when she needed assistance. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G3 | During the past month, you've complimented the way she was coping with your illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G4 | During the past month, you've seemed not to enjoy being around her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G5 | During the past month, you've made her wait a long time for help when she needed it. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G6 | During the past month, you've made it comfortable for her to share with you how she was feeling. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G7 | During the past month, you've avoided being around her when she was not feeling well. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G8 | During the past month, you've given her the idea you really did not want to talk about a problem she was having. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |

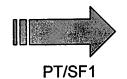
| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-----|--|--------------------------------|---------------------------------|------------------------------------|--------------------------------|--|--|
| G9 | During the past month, you've shouted or yelled at her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G10 | During the past month, you've made it a point to spend time with her when you thought she was feeling low. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G11 | During the past month, you've not seemed to respect her feelings. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G12 | During the past month, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G13 | During the past month, you've acted uncomfortable talking to her about how she was coping with your illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G14 | During the past month, you've criticized the way she was coping with your disease and/or its treatment. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G15 | During the past month, you've been affectionate with her when you thought she needed support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G16 | During the past month, you've acted less accepting of her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G17 | During the past month, you've not been emotionally supportive of her when she expected some support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |

The following questions concern your relationship with your wife <u>during the</u> <u>past month</u>. Please circle the response that best describes your thoughts and feelings about each statement.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-------------|--|----------------------|-----------|-------|-------------------|--|--|
| moi turr | AMPLE: During the past of the high street of the hi | Strongly Disagree | Disagree. | Agree | Strongly | | |
| Н1 | During the past month, I have been able to depend on my wife to help me if I really need it. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H2 | During the past month, I have not been able to turn to my wife for guidance in times of stress. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| Н3 | During the past month, my wife has enjoyed the same social activities I do. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H4 | During the past month, I have felt personally responsible for my wife's well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H5 | During the past month, I have not thought that my wife respected my skills and abilities. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| Н6 | During the past month, if something went wrong my wife would not come to my assistance. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H7 | During the past month, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H8 | During the past month, my wife has recognized my competence and skill. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H9 | During the past month, my wife has not shared my interests and concerns. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | |
|-----|--|----------------------|----------|-------|-------------------|--|
| H10 | During the past month, my wife has not really relied on me for her well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H11 | During the past month, my wife has been a trustworthy person I could turn to for advice if I were having problems. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H12 | During the past month, I have lacked a feeling of intimacy with my wife. | Strongly Disagree | Disagree | Agree | Strongly Agree | |

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.

<u>Does your health now limit you in these activities?</u> If so, how much? Please circle your response.

| ACTIVITIES | CIRCLE RESPONSE | | | | | |
|--|-----------------------|-------------------------|------------------------|--|--|--|
| EXAMPLE: Lifting or carrying groceries | Yes, limited a lot | Yes, limited a little (| No, not limited at all | | | |
| I1. Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I3. Lifting or carrying groceries | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I4. Climbing several flights of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I5. Climbing one flight of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I6. Bending, kneeling, or stooping | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I7. Walking more than a mile | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I8. Walking several blocks | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I9. Walking one block | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I10. Bathing or dressing yourself | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities <u>as a result of your **PHYSICAL**</u> **HEALTH**? Please circle YES or NO for each question.

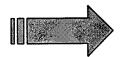
| PROBLEMS AS A RESULT OF PHYSICAL HEALTH | CIRCLE R | ESPONSE |
|--|----------|---------|
| EXAMPLE: Accomplished less than you would like | Yes | No. |
| I11. Cut down on the amount of time you spent on work or other activities | Yes | No |
| I12. Accomplished less than you would like | Yes | No |
| I13. Were limited in the kind of work or other activities | Yes | No |
| I14. Had difficulty performing the work or other activities (for example, it took extra effort) | Yes | No |
| I15. Cut down on the amount of time you spent on work or other activities | Yes | No |
| I16. Accomplished less than you would like | Yes | No |
| I17. Didn't do work or other activities as carefully as usual | Yes | No |
| | | · |
| | | |

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These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks ...

| | FEELINGS | | CIRCLE RESPONSE | | | | | | | |
|---|---|-----------------|------------------|------------------------------|------------------|----------------------|------------------|--|--|--|
| 200000000000000000000000000000000000000 | AMPLE: Have you felt calm and peaceful? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |
| I18. | Did you feel full of pep? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |
| I19. | Have you been a very nervous person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |
| I20. | Have you felt so down in the dumps that nothing could cheer you up? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |
| I21. | Have you felt calm and peaceful? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |
| I22. | Did you have a lot of energy? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |
| I23. | Have you felt downhearted and blue? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |
| I24. | Did you feel worn out? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |
| I25. | Have you been a happy person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |
| I26. | Did you feel tired? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | | |

| | | | | | | -, | | | |
|---|-----------|---|--|--------------------------------|--|--------------------|--|--|--|
| ^I 27. During the past 4 weeks , how much of the time has your physical health or emotional problen interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response. | | | | | | | | | |
| | • | 2 | 3 | | | 5 | | | |
| All | of | Most of | Some of | f | A little of | None of | | | |
| | time | the time | the time | • | the time | the time | | | |
| ^I 28. | interfere | ne past 4 weeks , to what d with your normal social ircle your response. | extent has you lactivities with fa | r physical he amily, friend | ealth or emotional s, neighbors, or g | problems roups? | | | |
| | 4 | 2 | 3 | | 1 | 5 | | | |
| Not | at all | 2 Slightly | Moderatel | у | Quite a bit | Extremely | | | |
| I _{29.} | How muc | ch bodily pain have you | had during the r | oast 4 week | s? Please circle y | our response. | | | |
| | | 2 | 2 | 1 | 5 | 6 | | | |
| No | ne | 2 Very mild | Mild | Moderate | Severe | Very severe | | | |
| ^I 30. | During th | ne past 4 weeks , how mo | uch did pain inte ework)? Please o | erfere with your re | our normal work (i esponse. | ncluding both | | | |
| | 4 | 0 | 2 | | 4 | 5 | | | |
| Not | at all | 2 Slightly | Moderatel | у У | Quite a bit | Extremely | | | |
| | | | | | | | | | |



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

| STATEMENT | | | | | | CIRCLE RESPONSE | | | |
|---|---------|----------------|---------|-----------------|----|-----------------|-----------------------------|-------|----------------------------------|
| EXAMPLE: I expect my health to get worse. Definitely true. Mostly true. | | | | | No | ot sure. | Mostl | | Definitely false. |
| I31. I seem to get sick a little easier than other people. | | Defini true | - ; | Mostly true. | N | ot sure. | Mostly fa | alse. | Definitely false. |
| I32. I am as healthy as anyone I know. | | Defini true | - | Mostly true. | N | ot sure. | Mostly fa | alse. | Definitely false. |
| I33. I expect my health to get worse. | | Defini true | • | Mostly true. | N | ot sure. | Mostly false. | | Definitely false. |
| I34. My health is exce | ellent. | Defini true | - | Mostly true. | N | ot sure. | Mostly false. | | Definitely false. |
| I35. In general, would Please circle you | | | lth is: | | | | | | ; |
| Excellent | Very (| Good | | Good | | F | air | | Poor |
| I36. Compared to one year ago, how would you rate your health in general now? Please circle your response. | | | | | | | | | |
| Much better now than one year ago. Somewhat better now than one year ago. | | | | ut the same. | | now th | nat worse an one ago. | 1 | uch worse now n one year ago. |

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

| J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response. | | | | | | | | | |
|--|---|--------------------|------------|---------------|--------------------------------------|-------------|---------------------|---------------|--|
| Every day | Abou | About once a week. | | | Less than once a week. | | | ot at all. | |
| J2. Which of the follow your response. | ving best | describes | your urin | nary cont | rol during the | e last | 4 weeks? F | Please circle | |
| No control whatsoever. | • | | | Occa | Occasional dribbling. Total control. | | | | |
| | J3. How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks? Please circle your response. | | | | | | | | |
| 3 or more pads pe | r day. | | 1-2 pad | ds per day. | | | No pads. | | |
| How big a problem, if | any, has | each of the | e followir | ng been f | or you? Pleas | se circ | le your resp | oonse. | |
| J4. Dripping urine or wetting your pants | 1 | problem | • | small blem | Small problem | 1 | loderate problem | Big problem | |
| J5. Urine leakage interfering with your sexual activity. | No problem Very smal problem | | | , | Small problem | | loderate problem | Big problem | |
| | J6. Overall, how big a problem has your urinary function been for you during the last 4 weeks? Please circle your response. | | | | | | | | |
| 1 | 2 | | | | | 4 | | 5 | |
| No problem | o problem Very S Small problem p | | | | | oderate Big | | | |

BOWEL HABITS: This section is about your bowel habits and abdominal pain. Please consider **ONLY THE LAST 4 WEEKS**.

| J7. How often I Last 4 wee | J7. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the Last 4 weeks? Please circle your response. | | | | | | | | |
|--|---|------------------|--------------------------------|-----------------------|-------------|--|--|--|--|
| 1 | 2 | 3- | | 4 | 5 | | | | |
| More than | About once | More th | an once | About once | Rarely | | | | |
| | a day | | eek | a week | or never | | | | |
| J8. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Please circle your response. | | | | | | | | | |
| 1 | 22 | 3- | | 4 | 5 | | | | |
| Never | Rarely | About the tir | half ne | 4 Usually | Always | | | | |
| Please circ | le your response | -2 | | | | | | | |
| | have you had c cle your respons | | ır abdomen or p | elvis during the las | st 4 weeks? | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | | | | |
| | | | | About once this month | | | | | |
| | J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks? Please circle your response. | | | | | | | | |
| 1 | 2 | 3 | ,,,*220 <i>23,</i> 22202072450 | 4 | 5 | | | | |
| Big | Moderate | Sma | II | Very small | No | | | | |
| problem | problem | proble | em | problem | problem | | | | |

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY. Please answer honestly about **THE LAST 4 WEEKS ONLY**.

| How has each of the following been for you? Please circle your response. | | | | | | | | |
|---|---|--------------------------|-----------|--------------|---|--|-------|-------------------------------|
| J12. Your level of sexual desire | Very poor sexual desire? | | Poo | Poor Fair | | Goo | od | Very good |
| J13. Your ability to have an erect | | Very poor | Poo | or | Fair | Good | | Very good |
| J14. Your ability to reach orgasm (climax)? | | Very poor | Poo | or | Fair | Good | | Very good |
| J15. How would yo | ou describe | e the usual | QUALITY o | of your erec | tions? Plea | se circle | your | response. |
| None at all. | Not | firm enoug sexual act | | mastu | enough for rbation and play only. | \$ | | rm enough for intercourse. |
| J16. How would yo | ou describ | e the FREC | QUENCY of | your erecti | ons? Pleas | e circle y | our r | esponse. |
| I NEVER had an erection when I wanted one. | erection when I LESS THAN HALF ABOUT HALF the MORE THAN HALF WHENEVER I | | | | | | | |
| J17. How often have you awakened in the morning or night with an erection? Please circle your response. | | | | | | | | |
| 110101 1000 111111 1 1 1 1 1 1 1 1 1 1 | | | | | | Very often (more n 75% of the time) | | |

| J18. During the last 4 weeks, did you have vaginal or anal intercourse? Please circle your response. | | | | | | | | | |
|--|---|---|-----------------|---------------------|--|--|--|--|--|
| No | | Yes, once | Yes | Yes, more than once | | | | | |
| J19. Overall, how circle your r | | exually during the last | 4 weeks? Please | | | | | | |
| 4 | 2 | 2 | Δ | 5 | | | | | |
| Very poor | Poor | 3 Fair | Good | Very good | | | | | |
| Please circl | J20. Overall, how big a problem has your sexual function been for you during the past 4 weeks? Please circle your response. | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | | | | | |
| No | Very | Small | Moderate | Big | | | | | |
| problem | small problem | n problem | problem | problem | | | | | |
| circle your r 1 Extremely | 2 | 3 Uncertain | 4 Satisfied | Extremely | | | | | |
| dissatisfied | | | | satisfied | | | | | |
| 1 No I | f no please go to | ce your treatment for proquestion K1. to question J22b. | estate cancer? | | | | | | |
| | o your erections esponse. | require assistance? Plea | ase mark your | | | | | | |
| 1 2 | 1 No If no, please go to question K1. 2 Yes If yes, please indicate which method you use. | | | | | | | | |
| | 2 Yes If yes, please indicate which method you use. Viagra Vasomax Penile Injections Urethral Suppositories (MUSE) Vacuum Device Constriction Ring Other Please specify: | | | | | | | | |

Please answer the following questions related to your prostate cancer diagnosis.

| K1. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response. | | | | | | | | | |
|---|--|---------------------------------|-------------------------|------------|--|--|--|--|--|
| 1 | 22 | 3 | 4 | 5 None | | | | | |
| A little | A moderate | A lot amount | A great | deal | | | | | |
| K2. Did a doctor ever talk to you about your PSA level after surgery? Please mark your response. | | | | | | | | | |
| 1 Yes (G | io to K3a) | | | | | | | | |
| level aft | K3a. How satisfied were you with the discussion that you had with your doctor about your PSA level after surgery? Please circle your response; then go to question K4. | | | | | | | | |
| Not at all | Slightly | Moderately | Quite a lot | Completely | | | | | |
| satisfied | satisfied | satisfied | satisfied | satisfied | | | | | |
| 2 No (Go K3b. Do you your PS 3 Don't k | wish you'd had the opp A level after surgery? | oortunity to talk to you YES | ır doctor about _ NO | | | | | | |
| K4. Do you kr | now your last PSA valu | e? | | | | | | | |
| 1 YES | If Yes, please write it | here: F | PSA value (ng/ml) | | | | | | |
| 2 NO | If No, please mark or | ne of the following op | tions: | | | | | | |
| | 2aI don't re | emember my last PSA | value. | | | | | | |
| | 2b I have no | ever been told my PS | A value. | | | | | | |
| | | | | | | | | | |

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| | | | ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,, | | | | | | | |
|---|-------------------|-------------------|--|---|------------------|-----------|--|--|--|--|
| K5. Do you know what different PSA levels mean? Please mark your response. | | | | | | | | | | |
| 1 No | | | | | | | | | | |
| 2. Yes | 2 Yes 3 Unsure | | | | | | | | | |
| 3 Uns | ure | | | | | | | | | |
| | | | | - | | | | | | |
| K6. Has a doctor ever talked to you about how your PSA level will be used to follow your treatment of prostate cancer? Please mark your response. | | | | | | | | | | |
| 1 No | | | | | | | | | | |
| 2. Yes | ; | | | | | | | | | |
| 1 No 2 Yes 3 Dor | i't know | | | | | | | | | |
| | | | | | | | | | | |
| K7 What do | you think | is the chance tha | nt you will have a re | ecurrence | of prostate canc | er after | | | | |
| your tre | eatment? Pl | lease circle your | response. | ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,, | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | | | |
| No | Very | Unlikely | Moderate | Likely | Very | Certain | | | | |
| chance | unlikely | | chance | | likely | to happen | | | | |
| K8. How worried are you that you will have a recurrence of prostate cancer? Please circle your response. | | | | | | | | | | |
| 1 | | 2 | 3 | | 4 | 5 | | | | |
| Not at all | (| Slightly | Moderately | ` | Very | Extremely | | | | |
| worried | | vorried | worried | | worried | worried | | | | |
| | | | | | | | | | | |
| | | | | | | | | | | |

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Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

| 2007/11/2008/2008 | MPLE: I feel that my efforts noticed and rewarded. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
|-------------------|---|----------------------|----------------------|----------------------------------|-------------------|-------------------|
| L1 | I feel that I get what I am entitled to in life. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L2 | I feel that my efforts are noticed and rewarded. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L3 | I feel that people treat me fairly. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L4 | I feel that I earn the rewards and punishments I get. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L5 | I feel that when I meet with misfortune, I have brought it upon myself. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L6 | I feel that I get what I deserve in life. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L7 | I feel that people treat me with the respect that I deserve. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L8 | I feel the world treats me fairly. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L9 | I basically believe the world is a fair place. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

| EXAMPLE: Until 1 No clear goals or purpose at all | 2 | | | _5 | 67 Very clear goals and purpose | |
|--|----------------|--------------|---------------|-----------------------|----------------------------------|--|
| M1. Do you have fe your response. | | ou don't rea | lly care what | goes on arou | ind you? Please circle | |
| 1 Very seldom or never | 2 | 3 | 4 | 5 | 67 Very often | |
| M2. Has it happene thought you kr | | | | | ior of people whom you | |
| 1 Never happened | 2 | 3 | 4 | 5 | 67 Always happened | |
| M3. Has it happene response. | ed that people | whom you | counted on | disappointed <u>y</u> | you? Please circle your | |
| 1 Never happened | 2 | 3 | 4 | 5 | 7 Always happened | |
| M4. Until now, your | life has had: | | | | | |
| 1 No clear goals or purpose at all | 2 | 3 | 4 | 5 | 6Very clear goals and purpose | |

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| M5. Do you have | the feeling tha | t you're being | g treated unfa | irly? Please | circle your resp | onse. |
|---|----------------------------------|-------------------------------|------------------------------|---------------------------------|--------------------------------------|------------------------|
| 4 | 2 | 3 | 4 | 5 | 6 | -7 |
| Very often | | | • | . | very s | eldom ever |
| M6. Do you have Please circle | the feeling tha your response | t you are in a | ın unfamiliar s | situation and | don't know wha | t to do? |
| 1 | 2 | 3 | 4 | 5 | 6 | -7 |
| Very often | - | Č | • | - | Very s | eldom ever |
| M7. Doing the thin | ngs you do eve | ery day is: | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | -7 |
| A source of deep pleasure and satisfaction | - | _ | • | | A soul | rce of pain boredom |
| M8. Do you have | • | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | -7 |
| Very often | | | | | Very s | eldom ever |
| M9. Does it happ your respon | | ve feelings ir | nside that you | ı would ratheı | r not feel? Pleas | se circle |
| 1 | 22 | 3 | 4 | 5 | 6 | - 7 |
| Very often | - | Ü | • | Ç | Very s | |
| M10. Many peopl (losers) in c circle your r | ertain situation | with a strong s. How often | g character— have you fel | sometimes fe t this way in t | eel like sad sack he past? Please | (S |
| 1 | | 3 | 4 | 5 | 6 | 7 |
| Never | _ | • | | | Very o | often |
| | | | | | | |

| M11. When somethi | ng happen | ed, have you | generally fou | nd that: | | |
|---------------------------------------|--------------|---------------|------------------|-------------|--|---------------|
| 1 | 2 | 33 | 4 | 5 | 6 | 7 |
| You overestimated | Z | - | | 0 | | ou saw things |
| Or underestimated | | | | | | in the right |
| its importance | | | | | | proportion |
| M12. How often do y life? Please c | rcle your re | esponse. | | | | |
| | 2 | 3 | 4 | 5 | | ery seldom |
| Very often | | | | | Ve | or never |
| M13. How often do y | ou have fe | elings that y | ou're not sure | you can kee | p under con | trol? |
| 1 | 2 | 3 | 4 | 5 | | |
| Very often | | | | | V | ery seldom |
| | | | | | | or never |
| Q1. Did anyone a No | • | - | letion of this s | urvey? | , | |
| No If | yes, who? | | | | ······································ | _ |
| | | | | | | |

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the third questionnaire six months from your treatment and/or management initiation date.

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Appendix D Six Month Questionnaire

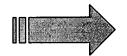
WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope within 1 week of receipt.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your spouse, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

| | GENERAL BACKGROUND INFORMATION - PLEASE | PRINT. | ; |
|-----|---|--------|---|
| A1. | Today's date://// | | |
| A2. | Name: | | ; |
| A3. | Home Address:Street | Apt. # | |
| | City State Zip Code | | |
| A4. | Home Phone Number: () | | : |
| | Alternate Phone Number: () | | |



The following statements are about your thoughts and feelings **since beginning your treatment for and/or management of prostate cancer.** Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

| | THOUGHTS AND FEELINGS | | CIRCLE RESPONSE | | | | | | |
|--|---|----------------------|-----------------|-----------|-------|-------------------|--|--|--|
| ** SANGE AND CONTROL OF THE PARTY OF THE PAR | MPLE: The purpose of each timent is clear to me. | Strongly Disagree | 7 | Undecided | Agree | Strongly Agree | | | |
| C1 | I do not know what is wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C2 | I have a lot of questions without answers. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C3 | I am unsure if my illness is getting better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C4 | It is unclear how bad my incontinence will be. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C5 | The explanations they give about my condition seem hazy to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C6 | The purpose of each treatment is clear to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C7 | When I have impotence, I know what this means about my condition. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C8 | I do not know when to expect things will be done to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| С9 | My symptoms/side effects continue to change unpredictably. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C10 | I understand everything explained to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |
| C11 | The doctors say things to me that could have many meanings. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | | |

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The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-----|--|----------------------|----------|-----------|-------|-------------------|--|
| C12 | I can predict how long my illness will last. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C13 | My treatment is too complex to figure out. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C14 | It is difficult to know if the treatments or medications I am getting are helping. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C15 | There are so many different types of staff, it is unclear who is responsible for what. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C16 | Because of the unpredictability of my illness, I cannot plan for the future. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C17 | The course of my illness keeps changing. I have good days and bad days. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C18 | It is vague to me how I will manage my care now that I've left the hospital. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C19 | I have been given many differing opinions about what is wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C20 | It is not clear what is going to happen to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C21 | I usually know if I am going to have a good or bad day. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C22 | The results of my tests are inconsistent. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C23 | The effectiveness of my treatment is undetermined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | | |
|-----|---|----------------------|----------|-----------|-------|-------------------|--|--|
| C24 | It is difficult to determine how long it will be before I can care for myself. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C25 | I can generally predict the course of my illness. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C26 | Because of the treatment's side effects, what I can do and cannot do keeps changing. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C27 | I am certain they will not find anything else wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C28 | The treatment I am receiving has a known probability of success. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C29 | They have not given me a specific diagnosis. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C30 | My incontinence and impotence are predictable; I know when they are going to get better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C31 | I can depend on the clinic staff to be there when I need them. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C32 | The seriousness of my illness has been determined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| C33 | The doctors and nurses use everyday language so I can understand what they are saying. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |

The following statements are about your sense of control over your life <u>during</u> the past month. Please circle the response that best describes how you have thought and felt during the past four weeks.

| | SENSE OF CONTROL | CIRCLE RESPONSE | | | | | | |
|-----|--|----------------------|----------|-------------|-------|-------------------|--|--|
| mor | EXAMPLE: During the past month, most of my problems were due to bad breaks. | | Disagree |) Undecided | Agree | Strongly Agree | | |
| D1 | During the past month, there was no sense in planning a lot. If something is going to happen, it will. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D2 | During the past month, the really good things that happened to me were mostly luck. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D3 | During the past month, I was responsible for my own successes. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D4 | During the past month, I could do just about anything I really set my mind to. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D5 | During the past month, most of my problems were due to bad breaks. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D6 | During the past month, I had little control over the bad things that happened to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D7 | During the past month, my misfortunes were a result of the mistakes I made. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D8 | During the past month, I was responsible for my failures. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |

The next questions ask about marital attitudes and behaviors <u>during the past</u> <u>month.</u> Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

| | ATTITUDES AND BEHAVIORS | CIRCLE RESPONSE | | | | | | | | |
|------|--|---------------------------|-------------|------------------|-----------------|-----------|------------------|---------|-----------------|-------------------|
| | mple: During the past oth, our marriage has been ong. | Strongly Disagree | 1 | 2 | -3 | -4 | 5 | -6- | 7 | Strongly Agree |
| E1 | During the past month, we have had a good marriage. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Strongly Agree |
| E2 | During the past month, my relationship with my partner has been very stable. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Strongly Agree |
| E3 | During the past month, our marriage has been strong. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 6- | 7 | Strongly Agree |
| E4 | During the past month, my relationship with my partner has made me happy. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 6- | 7 | Strongly Agree |
| E5 | During the past month, I have really felt like part of a team with my partner. | Strongly Disagree | 1 | 2 | 3 | 4 | 5- | 6- | 7 | Strongly Agree |
| ever | On the scale below, circle the number ything considered, in your marriage <u>d</u> esents your response. | from 1-10 uring the pa | that bast m | oest de onth. | escrib Pleas | es th | e degr le the | ee of h | nappi er tha | iness, at best |
| | 134 | 5 | (| 3 - | 7 | 7 <u></u> | 8 | | 9 | 10 |
| , | Very unhappy | Ha _l | рру | | | | | Pe | rfect | ly happy |

In the space below, please answer the following questions.

| Programme of the second of the |
|--|
| ou cope |
| |
| |
| And the control of th |
| Acceptant |
| |
| |
| es annaes de des relacions de la companyo del companyo de la compa |
| |
| |
| |
| |
| |

The statements below are possible reactions that you may have had towards your wife. Please tell us how often you have responded this way <u>during the past month</u>.

| | THOUGHTS AND FEELINGS | | CIRCLE R | ESPONSE | |
|------------|--|--------------------------------|---------------------------------|------------------------------------|--------------------------------|
| | EXAMPLE: During the past month, you've seemed not to enjoy being around her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G1 | During the past month, you've acted impatient with her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G2 | During the past month, you've seemed angry or upset with her when she needed assistance. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G3 | During the past month, you've complimented the way she was coping with your illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G4 | During the past month, you've seemed not to enjoy being around her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G5 | During the past month, you've made her wait a long time for help when she needed it. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G6 | During the past month, you've made it comfortable for her to share with you how she was feeling. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G 7 | During the past month, you've avoided being around her when she was not feeling well. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G8 | During the past month, you've given her the idea you really did not want to talk about a problem she was having. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |

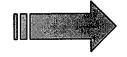
| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-----|--|--------------------------------|---------------------------------|------------------------------------|--------------------------------|--|--|
| G9 | During the past month, you've shouted or yelled at her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G10 | During the past month, you've made it a point to spend time with her when you thought she was feeling low. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G11 | During the past month, you've not seemed to respect her feelings. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G12 | During the past month, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G13 | During the past month, you've acted uncomfortable talking to her about how she was coping with your illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G14 | During the past month, you've criticized the way she was coping with your disease and/or its treatment. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G15 | During the past month, you've been affectionate with her when you thought she needed support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G16 | During the past month, you've acted less accepting of her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |
| G17 | During the past month, you've not been emotionally supportive of her when she expected some support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way | | |

The following questions concern your relationship with your wife <u>during the</u> <u>past month.</u> Please circle the response that best describes your thoughts and feelings about each statement.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-----|---|----------------------|----------|-------|-------------------|--|--|
| hav | AMPLE: During the past month, I be not been able to turn to my wife guidance in times of stress. | Strongly Disagree | Disagree | Agree | Strongly | | |
| H1 | During the past month, I have been able to depend on my wife to help me if I really need it. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H2 | During the past month, I have not been able to turn to my wife for guidance in times of stress. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| Н3 | During the past month, my wife has enjoyed the same social activities I do. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H4 | During the past month, I have felt personally responsible for my wife's well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H5 | During the past month, I have not thought that my wife respected my skills and abilities. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| Н6 | During the past month, if something went wrong my wife would not come to my assistance. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H7 | During the past month, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| Н8 | During the past month, my wife has recognized my competence and skill. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |
| H9 | During the past month, my wife has not shared my interests and concerns. | Strongly Disagree | Disagree | Agree | Strongly Agree | | |

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | |
|-----|--|----------------------|----------|-------|-------------------|
| H10 | During the past month, my wife has not really relied on me for her well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H11 | During the past month, my wife has been a trustworthy person I could turn to for advice if I were having problems. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H12 | During the past month, I have lacked a feeling of intimacy with my wife. | Strongly Disagree | Disagree | Agree | Strongly Agree |

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.

<u>Does your health now limit you in these activities?</u> If so, how much? Please circle your response.

| ACTIVITIES | CIRCLE RESPONSE | | | | | |
|--|-----------------------|--------------------------|------------------------|--|--|--|
| EXAMPLE: Lifting or carrying groceries | Yes, limited a lot | Yes, limited a (little | No, not limited at all | | | |
| I1. Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I3. Lifting or carrying groceries | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I4. Climbing several flights of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I5. Climbing one flight of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I6. Bending, kneeling, or stooping | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I7. Walking more than a mile | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I8. Walking several blocks | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I9. Walking one block | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |
| I10. Bathing or dressing yourself | Yes, limited a lot | Yes, limited a little | No, not limited at all | | | |

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities <u>as a result of your **PHYSICAL**</u> **HEALTH**? Please circle YES or NO for each question.

| PROBLEMS AS A RESULT OF PHYSICAL HEALTH | CIRCLE RESPONSE | | | |
|--|-----------------|-----|--|--|
| EXAMPLE: Accomplished less than you would like | Yes | ·No | | |
| I11. Cut down on the amount of time you spent on work or other activities | Yes | No | | |
| I12. Accomplished less than you would like | Yes | No | | |
| I13. Were limited in the kind of work or other activities | Yes | No | | |
| I14. Had difficulty performing the work or other activities (for example, it took extra effort) | Yes | No | | |

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

| EMOTIONAL PROBLEMS | CIRCLE RESPONSE | | |
|--|-----------------|----|--|
| I15. Cut down on the amount of time you spent on work or other activities | Yes | No | |
| I16. Accomplished less than you would like | Yes | No | |
| I17. Didn't do work or other activities as carefully as usual | Yes | No | |

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These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks ...

| | FEELINGS | CIRCLE RESPONSE | | | | | | |
|---|---|-----------------|------------------|------------------------|------------------------|----------------------|------------------|--|
| EXAMPLE: Have you felt calm and peaceful? | | All of the time | 9 m 2 | | Some of the time | A little of the time | None of the time | |
| I 18 . | Did you feel full of pep? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | |
| I 19 . | Have you been a very nervous person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | |
| I20. | Have you felt so down in the dumps that nothing could cheer you up? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | |
| I21. | Have you felt calm and peaceful? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | |
| I 22 . | Did you have a lot of energy? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | |
| I23. | Have you felt downhearted and blue? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | |
| I 24 . | Did you feel worn out? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | |
| I25. | Have you been a happy person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | |
| I26. | Did you feel tired? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | |

| interfered | e past 4 weeks , how I with your social activ rcle your response. | much of the t ities (like visit | ime has your ph ing with friends, | ysical health or en relatives, etc.)? | notional problems |
|--------------------------|--|------------------------------------|--------------------------------------|--|-------------------|
| All of | 2 Most of the time | So | -3 me of e time | A little of | None of the time |
| interfere Please ci | e past 4 weeks , to we d with your normal so rcle your response. | cial activities v | with family, frien | ds, neighbors, or g | roups? |
| 1 Not at all | 2 Slightly | 3 Mode | erately | 4 Quite a bit | 5 Extremely |
| ^I 29. How muc | ch bodily pain have yo | ou had during | the past 4 wee | ks? Please circle | your response. |
| 1 | 2 | 3 | | 5 | 6 |
| None | 2Very mild | Mild | Moderate | Severe | Very severe |
| | e past 4 weeks , how side the home and hou | | | | including both |
| 1 | 2 | | 3 | 4 | 5 |
| Not at all | Slightly | Mode | erately | Quite a bit | Extremely |
| | | | | | |



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

| STATEMENT | | | | | | CIRCLE RESPONSE | | | |
|--|----------------|----------------|---------------|-----------------|--|-----------------|-----------------------------------|-------|----------------------|
| EXAMPLE: I exp health to get wo | | Defini true | _ | Mostly true. | N | ot sure. | Mosti | | Definitely false. |
| I31. I seem to get sick a little easier than other people. | | Defini true | • | Mostly true. | THE CHANGES CONTRIBUTED TO THE C | Not sure. | Mostly fa | alse. | Definitely false. |
| I32. I am as healthy as anyone I know. | | Defini true | • | Mostly true. | | Not sure. | Mostly false. | | Definitely false. |
| I33. I expect my health to get worse. | | Defini true | • | Mostly true. | 1 | Not sure. | Mostly false. | | Definitely false. |
| I34. My health is excellent. | | Defini true | • | Mostly true. | | Not sure. | t sure. Mostly fals | | Definitely false. |
| I35. In general, wou Please circle yo | - | - | alth is: | | | | | | |
| Excellent | Very Good Good | | Good | | Fair | | | Poor | |
| I36. Compared to o | | | would | i you rate yoા | ur h | ealth in ge | neral now | ? | |
| Much better now than one year ago. Somewhat better now than one year ago. | | Abo | out the same. | | Somewhat worse now than one year ago. | | Much worse now than one year ago. | | |

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

| J1. Over | the past 4 week | s, how ofter | n have you leake | ed urine | e? Please circl | e your respons | se. | |
|--------------|---|----------------------|----------------------------|----------|-----------------------|-------------------------|---------------------|--|
| | Every day About once a week. | | | Less | than once a w | eek. N | lot at all. | |
| | ch of the following response. | best desci | ribes your urinar | y contro | ol during the | last 4 weeks? | Please circle | |
| No cont | trol whatsoever. Frequent dribbling. | | | Осс | asional dribbli | ng. To | tal control. | |
| | many pads or a | | | ı usuall | y use to contro | ol leakage dur i | ng the last 4 | |
| 3 (| or more pads per | day. | 1-2 pa | ds per | day. | No pads. | | |
| How big | a problem, if any | , has each | of the following | been fo | or you? Please | e circle your res | sponse. | |
| | oing urine or ng your s. | No proble | m Very sn proble | 1 | Small problem | Moderate problem | Big problem | |
| inter | e leakage fering with sexual rity. | No proble | problem Very sm problei | | Small problem | Moderate problem | Big problem | |
| | rall, how big a pro | | our urinary func | tion be | en for you dur | ing the last 4 | weeks? | |
| 1 No prob | lem V small | -2 ery problem | 3 Small proble | | | erate olem | 5 Big problem | |

BOWEL HABITS: This section is about your bowel habits and abdominal pain. Please consider **ONLY THE LAST 4 WEEKS**.

| | nave you had rec s? Please circle | tal urgency (felt like y your response. | you had to pas | s stool, but did n | ot) during the | | | | |
|---|---------------------------------------|---|-----------------------------------|---------------------------|----------------|--|--|--|--|
| 1 | 22 | 3 | | 4 | 5 | | | | |
| More than | About once | More than o | nce At | out once | Rarely | | | | |
| once a day | a day | a week | 7.2 | a week | or never | | | | |
| once a day | aday | a wook | | | | | | | |
| J8. How often I mushy) dur | nave you had sto ing the last 4 we | ols (bowel movemen eks? Please circle yo | ts) that were lo our response. | oose or liquid (no | form, watery, | | | | |
| 1 | 2 | 3 | | 4 | 5 | | | | |
| Never | Rarely | About half the time | | Usually | Always | | | | |
| Please circ | le your response | ur bowel movements | | | | | | | |
| • | Mo | | Little | | No | | | | |
| Severe | | | | distress | | | | | |
| distress | tress distress distress | | | | | | | | |
| J10. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks? Please circle your response. | | | | | | | | | |
| 4 | 0 | 3 | 4 | 5 | 6 | | | | |
| | | Several A | | | | | | | |
| Several | About once | times a week | a week | this month | or never | | | | |
| umes a day | a uay | unies a week | a week | uno monur | 01 110 01 | | | | |
| J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks? Please circle your response. | | | | | | | | | |
| | 4 | _ | | 4 | E | | | | |
| 1 | 2 | 3 | | 4 | 5 No | | | | |
| 1 Big | 2 Moderate | 33 Small | | 4 ery small | No | | | | |
| 1 Big problem | 2 Moderate problem | 3 Small problem | | 4 ery small oroblem | • | | | | |

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY. Please answer honestly about **THE LAST 4 WEEKS ONLY**.

| How has ead | ch of the | following be | en for y | ou? Ple | ease circle | you | r response. | | | |
|---|-----------|------------------------------|-----------|---------------------|---|--------|----------------------------------|--------|---------|------------------------------------|
| J12. Your level of sexual desire? | | kual ' | Very poor | | Poor | | Fair | C | Good | Very good |
| J13. Your ability to have an erection? | | ave an ' | Very poor | | Poor | | Fair | (| Good | Very good |
| J14. Your ability to reach orgasm (climax)? | | | | or | Poor | | Fair | (| Good | Very good |
| J15. How wo | uld you | describe the | usual C | UALIT | Y of your e | recti | ons? Please | circle | your | response. |
| None at | all. | 3 | enough | | Firm enough for masturbation and foreplay only. Firm enough for intercourse. | | | - | | |
| J16. How wo | uld you | describe the | FREQU | JENCY | of your er | ectio | ns? Please ci | rcle y | our re | esponse. |
| erection when I LESS THAN HALF ABOUT HALF the MORE THAN HALF WHENEVER | | | | | I had an erection WHENEVER I wanted one. | | | | | |
| J17. How ofte respons | | you awaker | ed in the | e morni | ing or nigh | t with | n an erection? | Plea | ase cir | cle your |
| Never | 1 | m (less thar of the time) | | often (l alf the | ess than time) | | ten (more tha nalf the time). | n | | often (more than % of the time) |

| J18. During the | last 4 weeks, did you h | nave vaginal or anal inte | rcourse? Please circle | your response. |
|-----------------|--|--|--------------------------|----------------|
| No | | Yes, once | Yes, mo | re than once |
| · | w would you rate your le your response. | ability to function sexual | lly during the last 4 we | eks? |
| 4 | 2 | 3 | | 5 |
| Very poor | Poor | 3 Fair | Good | Very good |
| Please circ | le your response. | our sexual function been | | |
| 1 | 2 | 3 | 4 | 5 |
| No | | Small | | |
| problem | small problem | problem | problem | problem |
| 1 | 2Dissatisfied | 3 Uncertain | 4Satisfied | 5 Extremely |
| dissatisfied | Diocanoca | | | satisfied |
| | had erections since you | our treatment for prostate stion K1. | e cancer? | |
| 2Yes | If yes, please go to qu | estion J22b. | | |
| | response. | iire assistance? Please r | | |
| 1 2 | No If no, p 2 Yes If yes, p | lease go to question K1. please indicate which me | ethod you use. | |
| | Viagra | | | |
| | Vasom | | | |
| | Penile | Injections | | |
| | | al Suppositories (MUSE) |) | |
| | Vacuu | m Device | • | |
| | | riction Ring | | |
| | Other | Please specify: | | |

Please answer the following questions related to your prostate cancer and the PSA (Prostate Specific Antigen) test.

The PSA is a relatively new test, and there is much to learn about how its use affects patients. While answering the questions below, if you are unsure of any words or terms, please make your best guess.

| K1. | Do you know why the PSA level is measured after surgery? | |
|-----|--|---|
| | 1 NO (if no, please go to K2) | |
| | 2 YES (If yes, please answer K1a) | |
| | K1a. In the space below please explain briefly why you think the PSA is measured after surgery. | |
| | | |
| K2. | Do you know what it means to have a detectable PSA level after surgery? | *************************************** |
| | 1 NO (if no, please go to K3) 2 YES (if yes, please answer K2a) | |
| | K2a. Please explain briefly what you think it means to have a detectable PSA level after surgery. | |
| | | |
| K3. | Do you think having a detectable PSA level after surgery means that prostate cancer s still present? | *************************************** |
| | 1 NO | |
| | 2 YES | |
| | 3 Don't know | |
| K4. | How many PSA tests have you had since surgery? (Number of tests) | |

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| K5. | When wa | as yoı | ır last PSA test? | | (1 | Date) | |
|----------|-----------------------|------------------|---|---|-------------------|--|---------------------|
| K6. | Do you k | now y | our last PSA valu | ue? | | | |
| | 1 | NO | (if no, please ma | rk one of the followin | g optio | ons and go to K7.) | |
| | | A | I don't reme | ember my last PSA va | alue. | | |
| | | B | I have neve | er been told my PSA v | /alue. | | |
| | 2 | YES | (if yes, please w | rite it here: | _ PS | A value (ng/ml) and | d go to K6a.) |
| | | K6a | How reassured circle your response | were you by the resu onse | Its of y | our last PSA test? | Please |
| | 1 | | 2 | 3 | | 4 | 5 |
| Not reas | at all sured | | Slightly reassured | Moderately reassured | | Very reassured | Extremely reassured |
| K7. | Was the than zer | | of your last PSA | test "not detectable' | " (son | netimes called "zero | " or "less |
| | 1 | NO | (if no, please go t | to K8) | | | |
| | 2 | Don't | know (please go | to K8) | | | |
| | 3 | I have | not had a PSA t | test since I had my su | ırgery | for prostate cancer. | (go to K8) |
| | 4 | YES | (if yes, please go | o to K7a.) | | | |
| | | K7a. | How reassuring (sometimes calle response. | is it to you that your led "zero" or "less thar | last Pt n zero | SA value was "not o ')? Please circle yo | letectable" our |
| | | | • | • | | 4 | E |
| | 1 at all suring | | Slightly reassuring | 3 Moderately reassuring | | Very reassuring | Extremely |
| K8. | | | ou'd had the oppo A test mean? | ortunity to talk more to | o your | doctor about what t | he results |
| | 1 2 3 | YES NO Don | 't know | | | | |

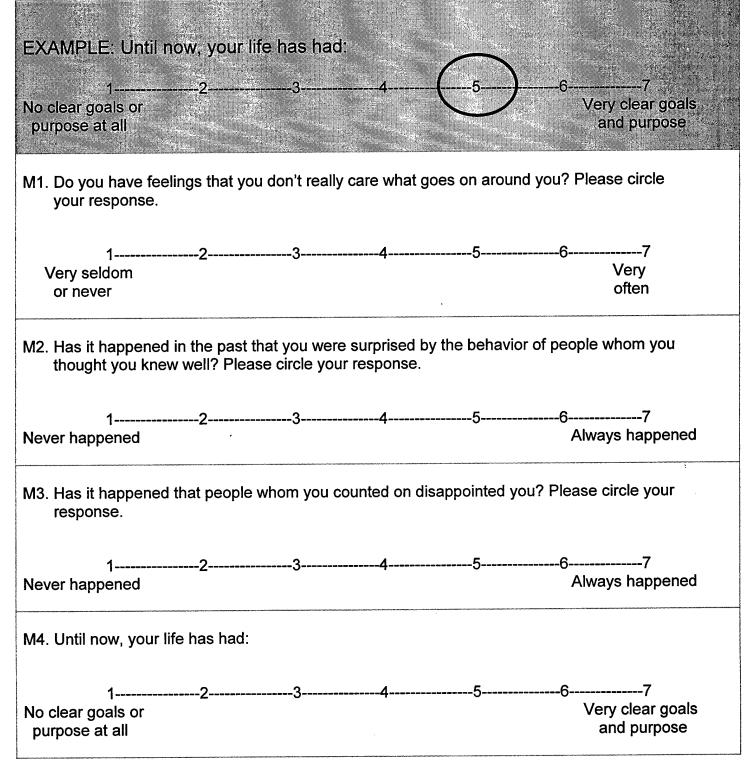
| K9. | Please | e circle | your response. | | nost recent PSA test(s | |
|-------------|---------------|---------------------|--------------------------------------|---|---|------------------------------|
| Not a | t all | | 2 Slightly worried | 33 Moderately worried | 4 y Very worried | Extremely d worried |
| K10. | | | are you about th your response. | e actual <u>number</u> o | of PSA tests you've ha | ad since surgery? |
| 1 | | | 2 | 3 | 4 | 5 |
| Not a | t all | | Slightly | Moderately worried | y Very | Extremely |
| K11. | Do you | u feel yo | ou've had the rig | ght amount of PSA | tests since your surg | ery? |
| | 1 | Shou | uld have had fev | ver (please go to l | <12) | |
| | 2 | — Num | ber of tests is a | bout right (please | go to K12) | |
| | | | | ore (if more, pleas | | |
| | | | | | | |
| | K11a | . How | many more tests | s do you think you | should have had? | • |
| K12. | How lo | ong afte | er surgery (mont ed? Please ente | hs or years) would er your response ir | you want to continue on the appropriate space | having your PSA se below. |
| | | | Months | OR | Years | |
| K13. | | | ever talked with cancer? | you about how the | PSA test will be used | I to help monitor |
| | 1 | _NO _YES | (If no, go to K1 (If yes, go to K | 4) 13a.) | | |
| | | test is circle y | used to help fol our response. | low you after your | loctor's explanations a surgery for prostate c | ancer? Please |
| 1 | | | 2 | 3 | 4 Very | 5 Completely |
| Not a satis | t all fied | | satisfied | satisfied | very satisfied | satisfied |

| K14. | Wha your | t do you think surgery? Plea | is the chance t se circle your r | hat you will have a esponse. | a recurrence of | f prostate ca | ncer after |
|--------------|-------------|---------------------------------|-------------------------------------|---------------------------------|-----------------|---------------|--|
| 1 | | 2 | 3 | 44 | 5 | 6 | 7 |
| No | | Very | Unlikely | Moderate chance | Likely | Very | Certain to happen |
| | your | response. | | have a recurrence | | | |
| 1 | | | 2 | 3 | 4 | | 5 Evtremely |
| Not a Wor | | Sil | gntly orried | Moderately worried | worri | y ied | worried |
| K16. | Befo | ore your surg | e ry , did you joi | n a prostate cance | er support grou | ıp? | Colonia de Carlo de C |
| | 1 | NO (if n | o, please go to | K17.) | | | • |
| | 2 | YES (if | ∕es, please go | to K16a.) | | | |
| | | prior 1 2 3 | to surgery? | wice a month | tate cancer sup | oport group | meetings |
| K17. | Afte | r your surger | y , did you join | a prostate cancer | support group | ? | |
| | | NO YES (if y | es, please go | to K17a) | | | |
| | | K17a. Abo | ut how often di | id you attend pros | tate cancer sup | pport group | meetings? |
| | | 1 | Severa | al times a week | | | |
| | | | About | | | | |
| | | | About | | | | |
| | | 4_ | About | once a month | | | |

Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

| 200 | MPLE: I feel that my efforts noticed and rewarded. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly | Strongly Agree |
|-----|---|----------------------|----------------------|----------------------------------|-------------------|-------------------|
| L1 | I feel that I get what I am entitled to in life. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L2 | I feel that my efforts are noticed and rewarded. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L3 | I feel that people treat me fairly. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L4 | I feel that I earn the rewards and punishments I get. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L5 | I feel that when I meet with misfortune, I have brought it upon myself. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L6 | I feel that I get what I deserve in life. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L7 | I feel that people treat me with the respect that I deserve. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L8 | I feel the world treats me fairly. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L9 | I basically believe the world is a fair place. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.



| M5. I | Do you have | the feeling that | you're being | treated unfai | rly? Please c | ircle your response. |
|-------|------------------------------------|---------------------------------|--------------------------------|--------------------------------|-----------------------------|--|
| • | 1 Very often | 2 | 3 | 4 | 5 | 67 Very seldom or never |
| | • | the feeling that your response. | you are in ar | n unfamiliar si | tuation and c | ion't know what to do? |
| , | 1Very often | 2 | 3 | 4 | 5 | 67 Very seldom or never |
| M7. I | Doing the thir | ngs you do ever | y day is: | | | |
| plea | 1urce of deep asure and tisfaction | 2 | 3 | 4 | 5 | 67 A source of pain and boredom |
| M8. I | Do you have | very mixed-up f | eelings and i | ideas? Pleas | e circle your ı | response. |
| • | 1 Very often | 2 | 3 | 4 | 5 | 67 Very seldom or never |
| | Does it happ your respons | | e feelings ins | side that you | would rather | not feel? Please circle |
| | 1Very often | 2 | 3 | 4 | 5 | 67 Very seldom or never |
| M10 | . Many people certain situa | e—even those v | with a strong n have you fe | character—s elt this way in | ometimes fe the past? Pl | el like sad sacks (losers) in ease circle your response. |
| | 1 Never | 2 | 3 | 4 | 5 | 67 Very often |

| in the right proportion 12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response. 1 | · • | | | | | |
|---|-------------------|----------------|-----------------|------------------|--------------|------------------------|
| or underestimated its importance in the right proportion M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response. 1234567 Very often Very seldom or never M13. How often do you have feelings that you're not sure you can keep under control? 13456 | //11. When someth | ing happened | d, have you ge | enerally found | that: | |
| or underestimated its importance in the right proportion ### 12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response. #### 1 | | | | | | _ |
| rou overestimated its importance in the right its importance in the right its importance in the right proportion in the right proportion. M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response. 1———2——3——4——5——6——7 Very often Very seldom or never M13. How often do you have feelings that you're not sure you can keep under control? 1———2——3——4——5——6——7 Very often Very seldom or never Q1. Did anyone assist you with the completion of this survey? | 1 | 2 | 3 | 4 | 5 | |
| its importance proportion M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response. 123456 | rou overestimateu | | | | | , 04 04 |
| M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response. 1——2——3——4——5——6——7 Very often Very seldom or never M13. How often do you have feelings that you're not sure you can keep under control? 1——2——3——4——5——6——7 Very often Very seldom or never Q1. Did anyone assist you with the completion of this survey? | | | | | | |
| life? Please circle your response. 1234567 Very often Very seldom or never M13. How often do you have feelings that you're not sure you can keep under control? 1234567 Very often Very seldom or never Q1. Did anyone assist you with the completion of this survey? | its importance | | | | | proportion |
| Very often W13. How often do you have feelings that you're not sure you can keep under control? 1234567 Very often Very seldom or never Q1. Did anyone assist you with the completion of this survey? | | | | nere's little me | aning in the | things you do in daily |
| Very often M13. How often do you have feelings that you're not sure you can keep under control? 1234567 Very often Very seldom or never Q1. Did anyone assist you with the completion of this survey? | 1 | 2 | 3 | 4 | 5 | 7 |
| N13. How often do you have feelings that you're not sure you can keep under control? 1234567 Very often Very seldom or never Q1. Did anyone assist you with the completion of this survey? | Very often | | - | · | | Very seldom |
| Q1. Did anyone assist you with the completion of this survey? | | | | | | or never |
| 17 Very often Very seldom or never Q1. Did anyone assist you with the completion of this survey? | | | lings that you | ro not ouro vo | u can keen | under control? |
| Q1. Did anyone assist you with the completion of this survey? | M13. How oπen do | you nave tee | elings that you | re not sure yo | u can keep | under control: |
| Q1. Did anyone assist you with the completion of this survey? | 1 | 2 | 3 | 4 | 5 | 7 |
| Q1. Did anyone assist you with the completion of this survey? | Verv often | | | | | Very seldom |
| Q1. Did anyone assist you with the completion of this survey? No | • | | | | | or never |
| Q1. Did anyone assist you with the completion of this survey? No If yes, who? | | | | | | |
| Q1. Did anyone assist you with the completion of this survey? No If yes, who? | | | | | | |
| Q1. Did anyone assist you with the completion of this survey? No You If yes, who? | | | | | | |
| Q1. Did anyone assist you with the completion of this survey? No If yes, who? | | | | | | |
| Q1. Did anyone assist you with the completion of this survey? No You If yes, who? | | | | | | |
| Q1. Did anyone assist you with the completion of this survey? No You If yes, who? | | | | | | |
| Q1. Did anyone assist you with the completion of this survey? No You If yes, who? | | | | | | |
| Q1. Did anyone assist you with the completion of this survey? No You If yes, who? | | | | | | |
| Vos If ves who? | Q1. Did anyone | assist you wit | th the complet | ion of this surv | vey? | |
| | Voc | If was who? | | | | |

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the fourth questionnaire twelve months from your treatment and/or management initiation date.

P:\DODPROST\FORMS\MATERIAL\6 month fu\6 m followup patient sp.final.080499.doc 09/23/99

Appendix E Twelve Month Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope within 1 week of receipt.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your spouse, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

| | GENERAL BACKGROUND INFORMATION - PLEASE | PRINT. |
|-------------|--|----------|
| A1. | Today's date://// | |
| A2. | Name: | . |
| A3. | Home Address:Street | Apt. # |
| | City State Zip Code | |
| A4. | Home Phone Number: () | |
| A5. | Date of Birth:///// | |
| A 6. | What is your highest level of education? (Put a checkmark by the ans | swer.) |
| | Grade school Some high school High school graduate Some college College graduate Graduate education | |
| A7. | Which of the following best describes your racial or ethnic backgroun | d? |
| | White, not of Hispanic origin Black or African-American, not of Hispanic origin Hispanic American Indian/Alaskan native Asian/Pacific Islander Hawaiian native Other (please specify). | |

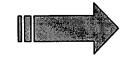
| A8. | Which of the following best describes your current relationship? |
|--|--|
| | Living with spouse or partner In a significant relationship, but not living together Not in a significant relationship |
| A9. | What is your current marital status? |
| | 1 Never married 2 Married 3 Separated 4 Divorced 5 Widowed |
| A10. | How long have you been married/separated/divorced/widowed? years |
| A11. | Who else lives in your household besides yourself? (Please check all that apply.) |
| | 1Your husband/wife 2Your mother 3Your father 4Your children 18 or under —> How many? 5Your children over 18 —> How many? 6Sister(s) —> How many? 7Brother(s) —> How many? 8Grandchildren —> How many? 9Grandparent(s) —> How many? 10Other relatives —> How many? 11Other non-relatives —> How many? 12I live by myself. |
| A12. | Here are several broad income ranges. Please select the range that most closely approximates <u>your</u> yearly household income, before taxes, from all sources, including social security. |
| 2 3 4 5 6 7 | 0 - \$4,000 2 |
| A13. | Altogether, how many people live on this income? |
| wire-reservation of the control of t | People. |

Do you have any of the following illnesses or conditions at the present time?

| | ILLNESS / CONDITION | | No or | If YES, circle how much the illness interferes with your daily activities | | | |
|-----|--|----|-------|---|----------|--------------|--|
| Exa | mple: Asthma | No | Yes | Not At All | A Little | A Great Deal | |
| B1 | Anemia | No | Yes | Not At All | A Little | A Great Deal | |
| B2 | Arthritis or rheumatism | No | Yes | Not At All | A Little | A Great Deal | |
| В3 | Asthma | No | Yes | Not At All | A Little | A Great Deal | |
| B4 | Cancer or leukemia | No | Yes | Not At All | A Little | A Great Deal | |
| B5 | Circulation trouble in arms, legs, or feet | No | Yes | Not At All | A Little | A Great Deal | |
| B6 | Depression, anxiety or emotional problems | No | Yes | Not At All | A Little | A Great Deal | |
| B7 | Diabetes | No | Yes | Not At All | A Little | A Great Deal | |
| B8 | Effects of Polio | No | Yes | Not At All | A Little | A Great Deal | |
| В9 | Effects of stroke | No | Yes | Not At All | A Little | A Great Deal | |
| B10 | Emphysema or chronic bronchitis | No | Yes | Not At All | A Little | A Great Deal | |
| B11 | Epilepsy/seizures | No | Yes | Not At All | A Little | A Great Deal | |
| B12 | Glaucoma | No | Yes | Not At All | A Little | A Great Deal | |
| B13 | Heart Disease | No | Yes | Not At All | A Little | A Great Deal | |
| B14 | High blood pressure (greater than 140/90) | No | Yes | Not At All | A Little | A Great Deal | |
| B15 | Kidney disease | No | Yes | Not At All | A Little | A Great Deal | |
| B16 | Liver disease | No | Yes | Not At All | A Little | A Great Deal | |
| B17 | Multiple Sclerosis | No | Yes | Not At All | A Little | A Great Deal | |

| | ILLNESS / CONDITION | | No or | If YES, circle how much the illness interferes with your daily activities. | | | |
|-----|---|----|-------|--|----------|--------------|--|
| B18 | Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome | No | Yes | Not At All | A Little | A Great Deal | |
| B19 | Other urinary tract disorders (including prostate trouble) | No | Yes | Not At All | A Little | A Great Deal | |
| B20 | Parkinson's Disease | No | Yes | Not At All | A Little | A Great Deal | |
| B21 | Severe memory problems such as Alzheimer's or other dementing illness | No | Yes | Not At All | A Little | A Great Deal | |
| B22 | Skin disorders such as pressure sores, leg ulcers, or severe burns. | No | Yes | Not At All | A Little | A Great Deal | |
| B23 | Thyroid or other glandular disorders | No | Yes | Not At All | A Little | A Great Deal | |
| B24 | Tuberculosis | No | Yes | Not at All | A Little | A Great Deal | |
| B25 | Stomach Ulcers | No | Yes | Not at All | A Little | A Great Deal | |
| B26 | Leg Amputation(s) | No | Yes | Not at All | A Little | A Great Deal | |

Please continue to the next page of the questionnaire.



The following statements are about your thoughts and feelings **since beginning your treatment for and/or management of prostate cancer.** Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

| | THOUGHTS AND FEELINGS | | Cl | RCLE RESPO | ONSE | |
|-----|---|----------------------|----------|-------------|-------|-------------------|
| 54 | MPLE: The purpose of each tment is clear to me. | Strongly Disagree | Disagree | Undecided (| Agree | Strongly Agree |
| C1 | I do not know what is wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C2 | I have a lot of questions without answers. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C3 | I am unsure if my illness is getting better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C4 | It is unclear how bad my incontinence will be. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C5 | The explanations they give about my condition seem hazy to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C6 | The purpose of each treatment is clear to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C7 | When I have impotence, I know what this means about my condition. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C8 | I do not know when to expect things will be done to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C9 | My symptoms/side effects continue to change unpredictably. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C10 | I understand everything explained to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
| C11 | The doctors say things to me that could have many meanings. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-----|--|----------------------|----------|-----------|-------|-------------------|--|
| C12 | I can predict how long my illness will last. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C13 | My treatment is too complex to figure out. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C14 | It is difficult to know if the treatments or medications I am getting are helping. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C15 | There are so many different types of staff, it is unclear who is responsible for what. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C16 | Because of the unpredictability of my illness, I cannot plan for the future. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C17 | The course of my illness keeps changing. I have good days and bad days. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C18 | It is vague to me how I will manage my care now that I've left the hospital. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C19 | I have been given many differing opinions about what is wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C20 | It is not clear what is going to happen to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C21 | I usually know if I am going to have a good or bad day. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C22 | The results of my tests are inconsistent. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C23 | The effectiveness of my treatment is undetermined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |

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The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

| | THOUGHTS AND FEELINGS | CIRCLE RESPONSE | | | | | |
|-----|---|----------------------|----------|-----------|-------|-------------------|--|
| C24 | It is difficult to determine how long it will be before I can care for myself. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C25 | I can generally predict the course of my illness. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C26 | Because of the treatment's side effects, what I can do and cannot do keeps changing. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C27 | I am certain they will not find anything else wrong with me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C28 | The treatment I am receiving has a known probability of success. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C29 | They have not given me a specific diagnosis. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C30 | My incontinence and impotence are predictable; I know when they are going to get better or worse. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C31 | I can depend on the clinic staff to be there when I need them. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C32 | The seriousness of my illness has been determined. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |
| C33 | The doctors and nurses use everyday language so I can understand what they are saying. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | |

The following statements are about your sense of control over your life <u>during</u> the past month. Please circle the response that best describes how you have thought and felt during the past four weeks.

| | SENSE OF CONTROL | CIRCLE RESPONSE | | | | | | |
|-----|--|----------------------|----------|-------------|-------|-------------------|--|--|
| mor | MPLE: During the past of my problems e due to bad breaks. | Strongly Disagree | Disagree |) Undecided | Agree | Strongly Agree | | |
| D1 | During the past month, there was no sense in planning a lot. If something is going to happen, it will. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D2 | During the past month, the really good things that happened to me were mostly luck. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D3 | During the past month, I was responsible for my own successes. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D4 | During the past month, I could do just about anything I really set my mind to. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D5 | During the past month, most of my problems were due to bad breaks. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D6 | During the past month, I had little control over the bad things that happened to me. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D7 | During the past month, my misfortunes were a result of the mistakes I made. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |
| D8 | During the past month, I was responsible for my failures. | Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree | | |

The next questions ask about marital attitudes and behaviors <u>during the past</u> <u>month.</u> Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions** without talking to your partner. Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

| | ATTITUDES AND BEHAVIORS | CIRCLE RESPONSE | | | | | | | | |
|-------------------------|---|---|--------|-------------------|-----------------|--------|---------------------|---------|---------------|-------------------|
| K: 80704-75, 3,30000000 | mple: During the past oth, our marriage has been ng. | Strongly Disagree | 1 | -2 | 3 | -4 | |)6 | 7 | Strongly Agree |
| E1 | During the past month, we have had a good marriage. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Strongly Agree |
| E2 | During the past month, my relationship with my partner has been very stable. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Strongly Agree |
| E3 | During the past month, our marriage has been strong. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Strongly Agree |
| E4 | During the past month, my relationship with my partner has made me happy. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Strongly Agree |
| E 5 | During the past month, I have really felt like part of a team with my partner. | Strongly Disagree | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Strongly Agree |
| ever | On the scale below, circle the number thing considered, in your marriage desents your response. | r from 1-10 to the particular | that b | est de onth. I | escrib Pleas | es the | e degre le the i | ee of h | appi r tha | ness, t best |
| | 134 | 5 | 6 | | 7 | , | 8 | | -9 | 10 |
| • | √ery unhappy | Ha _l | рру | | | | | Pei | rfect | y happy |

In the space below, please answer the following questions.

| F1. | During the past month, what has your wife said or done that you experienced as most annoying or That upset you, made you angry, or just somehow rubbed you the wrong way in regards to how you Are coping with prostate cancer? |
|-----|---|
| F2. | During the past month, what have you wished that your wife had done or said to help you cope with recovering from cancer that she did not do? |
| | |
| | |
| | |

The statements below are possible reactions that you may have had towards your wife. Please tell us how often you have responded this way **during the past month**.

| | THOUGHTS AND FEELINGS | | CIRCLE R | ESPONSE | |
|----|--|--------------------------------|---------------------------------|------------------------------------|--------------------------------|
| | EXAMPLE: During the past month, you've seemed not to enjoy being around her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G1 | During the past month, you've acted impatient with her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G2 | During the past month, you've seemed angry or upset with her when she needed assistance. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G3 | During the past month, you've complimented the way she was coping with your illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G4 | During the past month, you've seemed not to enjoy being around her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G5 | During the past month, you've made her wait a long time for help when she needed it. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G6 | During the past month, you've made it comfortable for her to share with you how she was feeling. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G7 | During the past month, you've avoided being around her when she was not feeling well. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G8 | During the past month, you've given her the idea you really did not want to talk about a problem she was having. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |

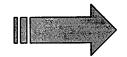
| | THOUGHTS AND FEELINGS | | CIRCLE R | ESPONSE | |
|-----|--|--------------------------------|---------------------------------|------------------------------------|--------------------------------|
| G9 | During the past month, you've shouted or yelled at her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G10 | During the past month, you've made it a point to spend time with her when you thought she was feeling low. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G11 | During the past month, you've not seemed to respect her feelings. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G12 | During the past month, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G13 | During the past month, you've acted uncomfortable talking to her about how she was coping with your illness. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G14 | During the past month, you've criticized the way she was coping with your disease and/or its treatment. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G15 | During the past month, you've been affectionate with her when you thought she needed support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G16 | During the past month, you've acted less accepting of her. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |
| G17 | During the past month, you've not been emotionally supportive of her when she expected some support. | Never responded this way | Rarely responded this way | Sometimes responded this way | Often responded this way |

The following questions concern your relationship with your wife <u>during the</u> <u>past month</u>. Please circle the response that best describes your thoughts and feelings about each statement.

| | THOUGHTS AND FEELINGS | | CIRCLE R | ESPONS | E |
|--|---|----------------------|----------|--------|-------------------|
| EXAMPLE: During the past month, I have not been able to turn to my wife for guidance in times of stress. | | Strongly Disagree | Disagree | Agree | Strongly |
| H1 | During the past month, I have been able to depend on my wife to help me if I really need it. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H2 | During the past month, I have not been able to turn to my wife for guidance in times of stress. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| Н3 | During the past month, my wife has enjoyed the same social activities I do. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H4 | During the past month, I have felt personally responsible for my wife's well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H5 | During the past month, I have not thought that my wife respected my skills and abilities. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H6 | During the past month, if something went wrong my wife would not come to my assistance. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H7 | During the past month, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H8 | During the past month, my wife has recognized my competence and skill. | Strongly Disagree | Disagree | Agree | Strongly Agree |
| H9 | During the past month, my wife has not shared my interests and concerns. | Strongly Disagree | Disagree | Agree | Strongly Agree |

| | THOUGHTS AND FEELINGS | | CIRCLE RESPONSE | | | |
|-----|--|----------------------|-----------------|-------|-------------------|--|
| H10 | During the past month, my wife has not really relied on me for her well-being. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H11 | During the past month, my wife has been a trustworthy person I could turn to for advice if I were having problems. | Strongly Disagree | Disagree | Agree | Strongly Agree | |
| H12 | During the past month, I have lacked a feeling of intimacy with my wife. | Strongly Disagree | Disagree | Agree | Strongly Agree | |

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day. **Does your health now limit you in these activities?** If so, how much? Please circle your response.

| ACTIVITIES | CIRCLE RESPONSE | | | | |
|--|-----------------------|----------------------------|------------------------|--|--|
| EXAMPLE: Lifting or carrying groceries | Yes, limited a lot | Yes, limited a (little | No, not limited at all | | |
| I1. Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports | Yes, limited a lot | Yes, limited a little | No, not limited at all | | |
| I2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | Yes, limited a lot | Yes, limited a little | No, not limited at all | | |
| I3. Lifting or carrying groceries | Yes, limited a lot | Yes, limited a little | No, not limited at all | | |
| I4. Climbing several flights of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | |
| I5. Climbing one flight of stairs | Yes, limited a lot | Yes, limited a little | No, not limited at all | | |
| I6. Bending, kneeling, or stooping | Yes, limited a lot | Yes, limited a little | No, not limited at all | | |
| I7. Walking more than a mile | Yes, limited a lot | Yes, limited a little | No, not limited at all | | |
| I8. Walking several blocks | Yes, limited a lot | Yes, limited a little | No, not limited at all | | |
| I9. Walking one block | Yes, limited a lot | Yes, limited a little | No, not limited at all | | |
| I10. Bathing or dressing yourself | Yes, limited a lot | Yes, limited a little | | | |

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities <u>as a result of your **PHYSICAL**</u> **HEALTH**? Please circle YES or NO for each question.

| PROBLEMS AS A RESULT OF PHYSICAL HEALTH | CIRCLE | RESPONSE |
|--|--------|----------------|
| EXAMPLE: Accomplished less than you would like | Yes | No |
| I11. Cut down on the amount of time you spent on work or other activities | Yes | No |
| I12. Accomplished less than you would like | Yes | No |
| I13. Were limited in the kind of work or other activities | Yes | No |
| I14. Had difficulty performing the work or other activities (for example, it took extra effort) | Yes | No : |

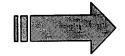
During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities <u>as a result of any **EMOTIONAL PROBLEMS**</u>, such as feeling depressed or anxious? Please circle YES or NO for each question.

| EMOTIONAL PROBLEMS | CIRCLE | RESPONSE |
|--|--------|----------|
| I15. Cut down on the amount of time you spent on work or other activities | Yes | No |
| I16. Accomplished less than you would like | Yes | No |
| I17. Didn't do work or other activities as carefully as usual | Yes | . No |

These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks ...

| | FEELINGS | CIRCLE RESPONSE | | | | | | | |
|---------------|---|--------------------|------------------|------------------------------|------------------|----------------------|------------------------|--|--|
| | AMPLE: Have you felt calm and peaceful? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I 18 . | Did you feel full of pep? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I 19 . | Have you been a very nervous person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I20. | Have you felt so down in the dumps that nothing could cheer you up? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I21. | Have you felt calm and peaceful? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I22. | Did you have a lot of energy? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I23. | Have you felt downhearted and blue? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I 24 . | Did you feel worn out? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I25. | Have you been a happy person? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |
| I26. | Did you feel tired? | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time | | |

| ^I 27. During the | past 4 weeks, how | much of the t | time has your ph | nysical health or en | notional problems |
|---|---|-------------------------------------|---|----------------------------|-------------------|
| | with your social actively governments. | vities (like visit | ting with friends, | relatives, etc.)? | |
| 1 | 2 | | 3 | 4 | 5 |
| All of | Most of | So | ome of | A little of | None of |
| • | the time | the | e time | the time | the time |
| interfered Please circ | past 4 weeks, to weith your normal socie your response. | cial activities | with family, frien | ds, neighbors, or g | groups? |
| 1 | | 3 | } | 4 | 5 |
| Not at all | 2 Slightly | Mod | erately | Quite a bit | Extremely |
| ^I 29. How much | n bodily pain have y | ou had during | the past 4 wee | ks? Please circle | your response. |
| 1 | 2 | 3 | 4 | 5 | 6 |
| None | Very mild | Mild | Moderate | Severe | Very severe |
| ^I 30. During the work outsi | e past 4 weeks, how de the home and ho | much did pa usework)? Ple | in interfere with ease circle your | your normal work response. | (including both |
| 1 | 2 | | .3 | 4 | 5 |
| Not at all | Slightly | Mod | erately | Quite a bit | Extremely |
| | *************************************** | | | | |



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

| STATEMENT | | | | | | CIRCLE RESPONSE | | | | |
|---|----------|---------------------|----------|-----------------|---|-----------------|----------------------------|-------|-------------------------------|--|
| EXAMPLE: I expect my health to get worse. | | Defini true | 1.15 | Mostly true. | N | ot sure. | Mostl | | Definitely false. | |
| I31. I seem to get sick a little easier than other people. | | Definitely true. | | Mostly true. | Not sure. | | Mostly false. | | Definitely false. | |
| I32. I am as healthy as anyone I know. | | Defini true | • | Mostly true. | N | Not sure. | Mostly fa | alse. | Definitely false. | |
| I33. I expect my hea | alth to | Definitely true. | | Mostly true. | \ | Not sure. | Mostly fa | alse. | Definitely false. | |
| I34. My health is exc | cellent. | Definitely true. | | Mostly true. | 1 | Not sure. | Mostly fa | alse. | Definitely false | |
| I35. In general, wou Please circle yo | | | alth is: | • | | | | | | |
| Excellent | Very (| Good | | Good | *************************************** | Fa | air | | Poor | |
| I36. Compared to one year ago, how would you rate your health in general now? Please circle your response. | | | | | | | | | | |
| Much better now than one year ago. Somewhat better now than one year ago. | | | | | | now th | at worse an one ago. | | ch worse now one year ago. | |

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

| J1. Over the past 4 weel | ks, how ofter | n have you leake | ed urine | e? Please circl | e your respons | e. · | | |
|--|---------------|---------------------|---------------|----------------------|------------------------|----------------|--|--|
| Every day | nce a week. | Less | than once a w | eek. N | ot at all. | | | |
| J2. Which of the followin your response. | g best descr | ibes your urinar | y contr | ol during the | last 4 weeks? | Please circle | | |
| No control whatsoever. | Freque | ent dribbling. | Occ | asional dribbli | ng. To | tal control. | | |
| J3. How many pads or a weeks? Please circ | | | ı usuall | y use to contro | ol leakage duri | ng the last 4 | | |
| 3 or more pads pe | r day. | 1-2 pa | ds per | day. | No pads. | | | |
| How big a problem, if an | y, has each | of the following | been fo | or you? Please | e circle your res | ponse. | | |
| J4. Dripping urine or wetting your pants. | No proble | m Very sm proble | | Small problem | Moderate problem | Big problem | | |
| J5. Urine leakage interfering with your sexual activit | No proble | m Very sn proble | 1 | Small problem | Moderate problem | Big problem | | |
| J6. Overall, how big a problem has your urinary function been for you during the last 4 weeks? Please circle your response. | | | | | | | | |
| 1 | 2 | 3 | | 4- | | 5 | | |
| No problem | | Small proble | | Mod | erate blem | Big problem | | |

BOWEL HABITS: This section is about your bowel habits and abdominal pain. Please consider **ONLY THE LAST 4 WEEKS**.

| 17. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks? Please circle your response. | | | | | | | | | |
|--|---|-----------------------|--|-----------------------|----------------|--|--|--|--|
| 1 | 22 | 3 | ###################################### | 4 | 5 | | | | |
| More than | About once a day | More than | once A | | | | | | |
| J8. How often have you had stools (bowel movements) that were loose or liquid (no form, water mushy) during the last 4 weeks? Please circle your response. | | | | | | | | | |
| 1 | 2 | 3 | | 4 | 5 | | | | |
| Never | Rarely | About hal the time | f | Usually | Always | | | | |
| | distress have your e your response. | | s caused you | during the last 4 v | weeks? | | | | |
| 1 | 2- | | 3 | | 4 : | | | | |
| Severe distress | Mode distre | rate | Little distres |) | No distress | | | | |
| | have you had cran cle your response. | npy pain in your a | bdomen or pe | elvis during the la | st 4 weeks? | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | | | | |
| Several | About once a day tir | Several | About once | About once this month | Rarely | | | | |
| | ow big a problem ha cle your response. | as your bowel hab | oits been for y | ou during the las | t 4 weeks? | | | | |
| 1 | 2 | 3 | | 4 | 5 | | | | |
| Big problem | Moderate problem | Small problem | ` | /ery small problem | No problem | | | | |

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY. Please answer honestly about THE LAST 4 WEEKS ONLY.

| How has ea | ch of the | e following | g been for y | ou? Pl | ease circle | your | response. | | | |
|---|--|--------------------------|-----------------------------|--------------------|---------------------------------------|---|--|------------------------------|--------|-------------------------------------|
| J12. Your level of sexual Desire? | | xual | Very poo | Γ | Poor | *************************************** | Fair | C | Good | Very good |
| | 3. Your ability to have an Very poor Erection? | | Very poor | | Poor | | Fair | C | ⊖ood | Very good |
| J14. Your ab Orgasm | ility to re | 3 | Very poo | r | Poor | | Fair | C | Good | Very good |
| J15. How wo | uld you | describe | the usual Q | UALIT | Y of your e | recti | ons? Please | circle | your | response. |
| None a | t all. | ì | firm enough sexual activ | | 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 | | | Firm enough for intercourse. | | |
| J16. How wo | ould you | describe | the FREQU | ENCY | of your er | ectio | ns? Please ci | rcle y | our r | esponse. |
| erection when I LESS THAN HALF ABOUT HALF the MORE THAN HALF WHENEVER | | | | | | | I had an erection WHENEVER I wanted one. | | | |
| J17. How oft Respon | | you awa | kened in the | e morn | ing or nigh | t with | an erection? | Plea | ase ci | rcle your |
| Never | | om (less t of the tim | | often (alf the | less than time) | | ten (more tha | n | - | often (more than 5% of the time) |

| J18. During the last 4 weeks, did you have vaginal or anal intercourse? Please circle your response. | | | | | | | | | | |
|--|--|--|------------------------|--------------|--|--|--|--|--|--|
| No | | Yes, once | Yes, mo | re than once | | | | | | |
| | J19. Overall, how would you rate your ability to function sexually during the last 4 weeks? Please circle your response. | | | | | | | | | |
| 1 | | 3 | 44 | 5 | | | | | | |
| Very poor | Poor | Fair | Good | Very good | | | | | | |
| | w big a problem has le your response. | your sexual function been | for you during the pas | st 4 weeks? | | | | | | |
| 1 | | 3 | 4 | 5 | | | | | | |
| No. | Very | Small | Moderate | Big | | | | | | |
| | small problem | problem | problem | problem | | | | | | |
| Please circ | cle your response. | vith the treatment you recei 3 Uncertain | 44 | | | | | | | |
| Dissausileu | | | | | | | | | | |
| 1 No | had erections since If no please go to qualifyes, please go to qualifyes, | your treatment for prostate uestion K1. | e cancer? | | | | | | | |
| 2103 | ii yoo, pioado go to t | 400.011 0225. | | | | | | | | |
| | Do your erections re response. | quire assistance? Please n | nark your | | | | | | | |
| 2 | I No If no 2 Yes If yes | please go to question K1. , please indicate which me | ethod you use. | | | | | | | |
| | Peni Peni Uret Vacu Con | ra omax le Injections hral Suppositories (MUSE) uum Device striction Ring er Please specify: | | | | | | | | |

Please answer the following questions related to your prostate cancer and the PSA (Prostate Specific Antigen) test.

The PSA is a relatively new test, and there is much to learn about how its use affects patients. While answering the questions below, if you are unsure of any words or terms, please make your best guess.

| K1. | Do you know why the PSA level is measured after surgery? |
|-----|---|
| | 1 NO (if no, please go to K2) |
| | 2 YES (If yes, please answer K1a) |
| | K1a. In the space below please explain briefly why you think the PSA is measured after surgery. |
| | |
| K2. | Do you know what it means to have a detectable PSA level after surgery? |
| | 1 NO (if no, please go to K3) 2 YES (if yes, please answer K2a) |
| | K2a. Please explain briefly what you think it means to have a detectable PSA level after surgery. |
| | |
| K3. | Do you think having a detectable PSA level after surgery means that prostate cancer is still present? |
| | 1NO |
| | 2YES |
| | 3 Don't know |
| K4. | How many PSA tests have you had since surgery? (Number of tests) |

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| K5. | When w | as your last PSA t | est? | | _ (Date) | | | | | | |
|------|-------------------------------------|--|--------------------------------|----------------------|---------------------------|---------------------------------|---------------------|--|--|--|--|
| K6. | 6. Do you know your last PSA value? | | | | | | | | | | |
| | 1 | NO (if no, pleas | e mark one | of the following | options ar | nd go to K7.) | | | | | |
| | | A I don't | remember | my last PSA val | ue. | | | | | | |
| | | B I have | never been | told my PSA va | alue. | | | | | | |
| | 2 | YES (if yes, plea | ase write it h | nere: | _ PSA valu | ue (ng/ml) ar | nd go to K6a.) | | | | |
| | | K6a. How reass circle your | | ou by the result | s of your la | ast PSA test? | Please | | | | |
| | 1 | 2 | | 3 | | 4 | 5 | | | | |
| Not | at all | Slightly reassured | | Moderately reassured | r | Very eassured | Extremely reassured | | | | |
| | | | | | | | | | | | |
| K7. | Was the than ze | e value of your last ro")? | t PSA test' | 'not detectable" | (sometime | es called "zer | o" or "less | | | | |
| | 1 | NO (if no, pleas | e go to K8) | | | | | | | | |
| | 2 | Don't know (plea | se go to K8 |) | | | | | | | |
| | 3 | I have not had a | PSA test sir | nce I had my sur | gery for pr | ostate cance | r. (go to K8) | | | | |
| | 4 | YES (if yes, plea | se go to K7 | a.) | | | | | | | |
| | | K7a. How reass (sometime response. | uring is it to s called "ze | you that your la | ast PSA va zero")? F | lue was "not Please circle y | detectable" /our | | | | |
| | 1 | 22 | | 3 | | 4 | 5 | | | | |
| Not | at all | Slightly | | Moderately | | Very | Extremely | | | | |
| reas | suring | reassuring | | reassuring | r | eassuring | reassuring | | | | |
| K8. | Do you v | vish you'd had the ast PSA test mea | opportunity | y to talk more to | your docto | or about what | the results | | | | |
| | 1 | _ YES | | | | | | | | | |
| | 2 | _ NO Don't know | | | | | | | | | |
| | <u> </u> | _ DOLL KITOW | | | | | | | | | |

| Please | rried are you about the circle your response. | | | 5 |
|----------------------|---|---|--|---------------------------|
| Not at all | 2 Slightly worried | Moderately worried | Very worried | Extremely |
| | orried are you about the circle your response. | actual <u>number</u> of P | 'SA tests you've had sin | ce surgery? |
| Not at all | Slightly | 3 Moderately worried | Very worried | 5 Extremely worried |
| K11. Do you | feel you've had the righ | t amount of PSA tes | sts since your surgery? | |
| 1 | _ Should have had fewe | er (please go to K12 | 2) | |
| 2 | Number of tests is ab | out right (please go | to K12) | |
| 3 | _ Should have had mor | e (if more, please g | go to K11a.) | |
| K11a. | How many more tests | do you think you sho | ould have had? | • |
| K12. How lor level m | ng after surgery (monthseasured? Please enter | s or years) would yo your response in th | u want to continue havir e appropriate space bel | ng your PSA ow. |
| | Months | OR | Years | |
| K13. Has a do | octor ever talked with you | ou about how the PS | SA test will be used to he | elp monitor |
| 1 2 | NO (If no, go to K14 YES (If yes, go to K1: |) 3a.) | | |
| | test is used to help follo circle your response. | w you after your sur | tor's explanations about gery for prostate cancer | ? Please |
| Not at all | Slightly | Moderately | Very satisfied | Completely |

| K14. Wh | nat do you think ur surgery? Plea | is the chance tase circle your | that you will have response. | a recurrence of p | rostate ca | incer after |
|-----------------------|--------------------------------------|---|------------------------------|-------------------|------------|---|
| 4 | 2 | 3 | 4 | 5 | 6 | 7 |
| No | Very unlikely | Unlikely | Moderate | Likely | Very | Certain to happen |
| | w worried are y ır response. | ou that you will | have a recurrenc | e of prostate can | cer? Plea | se circle |
| 1 | | -2 | 3 | 4 | | 5 |
| Not at all Worried | all Slightly | | Moderately worried | Very worried | d | Extremely worried |
| K16. <u>Be</u> | fore your surg | ery , did you joi | n a prostate canc | er support group | ? | CONTRACTOR |
| 1 | NO (if i | no, please go to | o K17.) | | | |
| _ | YES (if | - | | | | |
| _ | | , , , | , | | | |
| | | out how often dir r to surgery? | id you attend pros | tate cancer supp | ort group | meetings |
| | 1_ | Severa | I times a week | | | |
| | 2 | About o | once a week | | | |
| | 3 | About t | wice a month | | | |
| | 4 | About o | once a month | | | |
| K17. <u>Af</u> | ter your surge | r y , did you join | a prostate cancer | support group? | | |
| 1_ | NO | | | | | |
| | YES (if | es, please go | to K17a) | | | |
| _ | | , , , , J · · · · · · · · · · · · · · · | • | | | |
| | K17a. Abo | out how often d | id you attend pros | tate cancer supp | ort group | meetings? |
| | 1_ | Severa | al times a week | | | |
| | 2_ | About | once a week | | | |
| | 3 | About | twice a month | | | |
| | - | About | • | | | |

Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

| | MPLE: I feel that my efforts noticed and rewarded. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly | Strongly Agree |
|----|---|----------------------|----------------------|----------------------------------|-------------------|-------------------|
| L1 | I feel that I get what I am entitled to in life. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L2 | I feel that my efforts are noticed and rewarded. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L3 | I feel that people treat me fairly. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L4 | I feel that I earn the rewards and punishments I get. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L5 | I feel that when I meet with misfortune, I have brought it upon myself. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L6 | I feel that I get what I deserve in life. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L7 | I feel that people treat me with the respect that I deserve. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L8 | I feel the world treats me fairly. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |
| L9 | I basically believe the world is a fair place. | Strongly Disagree | Slightly Disagree | Neither Agree nor Disagree | Slightly Agree | Strongly Agree |

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Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

| Property of the Control of the Contr | Salar All Company | | 16. 13.114 | | the control of the co | | |
|--|----------------------|-------------------|--|--------------|--|--|--|
| EXAMPLE: Until n | ow, your li | fe has had | A STATE OF THE STA | | | | |
| 1———— No clear goals or purpose at all | 2 | 3 - 17 14 - 14 | | 5 | 7 Very clear goals and purpose | | |
| M1. Do you have feel your response. | ings that yo | u don't really | care what go | es on around | d you? Please circle | | |
| 1 | 2 | 3 | 4 | 5 | 6 - 7 | | |
| Very seldom | | Ü | • | · · | Very | | |
| or never | | | | | often | | |
| 1 Never happened | 2 | 3 | 4 | 5 | 67 Always happened | | |
| M3. Has it happened that people whom you counted on disappointed you? Please circle your response. | | | | | | | |
| 1 | 2 | . 3 | 4 | 5 | 7 | | |
| Never happened | - | • | • | - | Always happened | | |
| M4. Until now, your life has had: | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 7 | | |
| No clear goals or | - | - | - | | Very clear goals | | |
| purpose at all | | | | | and purpose | | |

| M5. Do you have the feeling that you're being treated unfairly? Please circle your response. | | | | | | |
|--|-----------------------------------|--------------------------------|----------------------------|------------------------------|--|--|
| 1 Very often | 2 | 3 | 4 | 5 | 67 Very seldom or never | |
| M6. Do you have t Please circle y | he feeling that your response. | you are in an | unfamiliar si | ituation and d | on't know what to do? | |
| 1 Very often | 2 | 3 | 4 | 5 | 67 Very seldom or never | |
| M7. Doing the thin | gs you do ever | y day is: | | | | |
| 1 A source of deep pleasure and satisfaction | 2 | 3 | 4 | 5 | 67 A source of pain and boredom | |
| M8. Do you have | very mixed-up f | feelings and i | deas? Pleas | e circle your r | response. | |
| 1 Very often | 2 | 3 | 4 | 5 | 67 Very seldom or never | |
| M9. Does it happo your respons | | e feelings ins | side that you | would rather | not feel? Please circle | |
| 1 Very often | 2 | 3 | 4 | 5 | 67 Very seldom or never | |
| M10. Many people certain situa | e—even those tions. How ofte | with a strong n have you fe | character—selt this way in | sometimes fe the past? Pl | el like sad sacks (losers) in ease circle your response. | |
| 1 Never | 2 | 3 | 4 | 5 | 7 Very often | |

| M11. When something happened, have you generally found that: | | | | | | | |
|--|--------------|----------------|----------------|---------------|-------------|---|--|
| 1 You overestimated or underestimated its importance | 2 | 3 | 4 | 5 | You ir | 7 I saw things In the right Proportion | |
| M12. How often do y life? Please cir | | | ere's little m | eaning in the | things you | do in daily | |
| 1 Very often | 2 | 3 | 4 | 5 | | 7 y seldom or never | |
| M13. How often do y | ou have feel | ings that you' | re not sure y | ou can keep | under contr | ol? | |
| 1Very often | 2 | 3 | 4 | 5 | Ver | 7 ry seldom or never | |
| Q1. Did anyone as No Yes If | • | | | | | . | |

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the fourth questionnaire twelve months from your treatment and/or management initiation date